SPIRITUAL INTERVENTION IN NEWLY DIAGNOSED CANCER PATIENTS UNDERGOING CHEMOTHERAPY

A THESIS

SUBMITTED TO THE FACULTY OF

GORDON-CONWELL THEOLOGICAL SEMINARY

IN PARTIAL FULFILLMENT OF REQUIREMENTS FOR THE DEGREE

DOCTOR OF MINISTRY

BY

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MAY 2007

DEDICATED TO:

My grandchildren for teaching me how to live in the now;

My patients for showing me how to live with difficulties;

My children for revealing God's love;

My mentor Louis Beach for seeing what no one else saw;

My wife for introducing me to grace and acceptance;

My parents for instilling a love of truth;

My friend Tommy Pirkle for valuable guidance; and

Mrs. Judy Bynum for directing me to Gordon-Conwell Theological Seminary.

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ABSTRACT

This study is the first to report on the development of spiritual intervention material designed to enhance spiritual transformation in newly diagnosed cancer patients undergoing chemotherapy. The intervention was based on peer patient narratives and was presented in video format for six consecutive weeks as either spiritually oriented or as factually oriented. The data reported herein represented a small sample size and interpretation is limited. Notwithstanding, several conclusion can be drawn from the study: (a) all patients watching spiritually oriented narrative (SON) videos would participate in another study and would recommend to a friend, and only half those participating in the factually oriented narrative (FON) videos would do so; (b) the spiritual transformation scale (STS) score of the SON group, even with only four patients, was significantly greater than the FON group; (c) the STS score of the FON group was similar to that reported previously for a large number of cancer patients and would suggest no effect of FON on the STS scores; and (d) previously discussed objections to physicians' inquiry into the spirituality of patients were shown not to be a valid concern in this population of patients. The results clearly demonstrate how a Christian physician can integrate faith and work, not only in spiritual history taking but also in spiritual intervention programs.

CHAPTER I

THE PROBLEM

> There is considerable evidence that a diagnosis of cancer disrupts one's world view and sense of wellbeing, at least initially. Additional studies suggest that while negative effects are prevalent, positive effects also occur and may even occur more frequently. Empirical data and anecdotal reports indicate that spiritual resources often play a role in the adjustment process for people facing medical illness, and cancer in particular. (Cole, 2004, p. 14)

What is the Problem?

"Cancer is the best thing that ever happened to me." (Daugherty, 2006, p. 59) How could such a statement be made about such an awful disease? Yet, the theme of transformation is not too uncommon when you hear or read the life stories of individuals with cancer. The life-threatening nature of cancer predisposes one to an increased awareness of one's meaning and purpose in life and often brings spiritual matters to the forefront.

This thesis proposes to develop spiritual intervention material specifically designed to enhance spiritual transformation in individuals newly diagnosed with cancer,

and to measure the changes in their spiritual transformation. The interventional material will be based on peer patient narratives that the author has collected over the years. As a Christian physician, in a predominately Christian community, training in a seminary Marketplace Ministry program, the author is uniquely suited to inquire, intervene and interpret spiritual issues.

Why is this a Problem?

Evidence suggests that positive emotional, religious, and spiritual change can come about as a result of early stage breast cancer and that having experienced a positive change predicts better adjustment (perceived quality of life, positive and negative affect and depression) several years after diagnosis (Carver and Antoni, 2004; Kristeller and Hummel, 2006). However, other studies of women including those with more advanced breast cancer gave contradictory results (Tomich and Helgeson, 2004). However, the studies differed in the time interval from diagnosis to assessment, different patient populations, and different measurements of benefit. Other investigators failed to find any relationship between initial benefit finding and distress one year later (Sears, Stanton, and Danoff-Burg, 2003). Recently investigations have suggested that these contradictory results may simply be due to subsets of patients that respond differently to cancer (Lechner, Carver, Antoni, Weaver, and Phillips, 2006).

Spiritual decline was associated with poorer adjustment (symptoms, treatment side effects, pain frequency and severity, physical functioning, depression, and anxiety) and interventions were recommended as a possible consideration for amelioration (Cole and Pargament, 1999). However, no interventions are currently available that are

designed to enhance spiritual transformation or to facilitate further spiritual growth. This thesis will address this deficiency.

Scientific studies of the spiritual transformation undergone by patients have heretofore been difficult. The first reported study of an intervention using religious or spiritual content in individuals diagnosed with cancer was recently reported (Cole, 2005). The study demonstrated benefit in pain severity and depression. The author of the study concluded:

> The data suggest that it is important for medical and psycho-social support services to support positive spiritual and religious coping efforts, identify people for whom negative spiritual and religious coping is present, and assist those people in resolving any underlying spiritual or religious based distress. The data also suggest that offering spiritually-focused interventions might be a viable means of addressing these and other issues in order to improve adjustment. (Cole, 2005, p. 224)

Assessment of spiritual transformation (Spiritual Transformation Scale; STS) in individuals with cancer has recently been reported (Cole, Hopkins, and Tisak, 2006). The STS assessed spiritual decline as well as spiritual growth, and was shown to be a psychometrically sound instrument (reliability and validity). Additional support was demonstrated for the association of spiritual growth with better mental and spiritual well-being. The development of the STS provides the first instrument to specifically assess spiritual transformations. Thus, a quantitative method is now available to study spiritual transformation in individuals diagnosed with cancer. Those individuals showing a

spiritual decline may represent the ones that would benefit most from spiritual intervention. Chapter III will provide a more comprehensive review of the literature.

How Will the Problem be Approached?

Central to the proposed study is spiritual transformation, primarily from a Christian perspective, occurring in patients diagnosed with cancer. Spiritual transformation is founded in several biblical passages that address the process (Rom 12.2 New International Version; Gal 4.19) as well as the purpose (Phil 2.5; 2 Cor 3.18). Spiritual transformation is counter-intuitive to suffering, yet Christians are told that it results in rejoicing (Rom 5.3) and joy (Jas 1.2). The chosen interventions reflect this type of spiritual transformation. The assessment of spiritual transformation will be done with the Spiritual Transformation Scale (STS). The STS is a newly developed religion-independent, Judea-Christian consistent, tool for measuring self-reported changes in spirituality in cancer patients (Cole et al. 2006). The theological framework of this study will be addressed in Chapter II.

Material will be developed, based on peer patient narratives that will be useful for spiritual intervention in a physician office and, at the same time, facilitate spiritual engagement. Cancer patients often seek encouragement and support from books, devotions, support groups, etc. As a medical oncologist the author has access to patient narratives that are spiritually oriented from a Christian perspective and demonstrate not only the ability to cope but frequently a transformative experience attributed to cancer. Peer patients' stories provided to the patients weekly may influence the patient's spirituality. The research will develop a series of six interventions based on peer patient

narratives. Each intervention will consist of an approximately five minute video in which the medical condition of the patient whose narrative will be used will be discussed followed by the patient's story. The choice to use the video format for the intervention follows from several studies: (a) reading can be a strain on cancer patients, especially those with low literacy skills (Doak, Doak, Friedell, and Meade, 1998); (b) a higher illiteracy rate in patients over 65 years of age where cancer has the greatest incidence (Weiss et al. 1994); (c) better comprehension has been demonstrated with video (Rossi, McClellan, Chou, and Davis, 2004; Phelan et al. 2001; Jimison, Sher, Appleyard, and LeVornois, 1998); and (d) experimental integrity is maintained in that each patient hears the same words from a familiar doctor.

The product produced by this study will be a six week intervention of spiritually oriented material developed with the intention of enhancing spiritual transformation in individuals diagnosed with cancer. The product is an example of how a Christian physician can integrate faith into his workplace

Newly diagnosed cancer patients will be offered the opportunity to participate in this study. After obtaining informed consent each patient will undergo a series of measurements of their religiosity, spirituality and overall well-being. When the patients start chemotherapy treatment they will be shown a different video weekly for six consecutive weeks. At the end of the intervention period they will be assessed using the STS. The complete protocol is included in Chapter IV. The data will be analyzed according to standard statistical methods and will be detailed in Chapter V.

CHAPTER II

BIBLICAL AND THEOLOGICAL FRAMEWORK

Do caterpillars know they're going to be butterflies, or does God surprise them? (Keane, 2006)

Introduction

The theological framework for this thesis is found in the exhortation of Paul to the Romans "but be transformed by the renewing of your mind" (Rom 12:2a); (*alla metamorphousthe te anakainosei tou nous*) (Romans 12:2, 2007). However, the thesis does not deal with the traditional view of sanctification regarding moral behavior as preached in our churches and seminaries. Rather, just as Romans 12:2 bridges between doctrinal concerns and practical concerns (Romans 12:2, 2007), this thesis deals with a more spiritually practical sanctification, primarily concerned with the inner perceptions, thoughts, and attitudes of people in everyday living with a life-threatening illness, namely cancer.

The theological themes connecting Rom 12:2a and this thesis include the following: (a) utilization of the work environment to enhance the intellectual, moral, and spiritual state of patients diagnosed with cancer; (b) recognition that suffering may be a catalyst for spiritual transformation; (c) cooperation of the Holy Spirit and the will of the

one being spiritually transformed; and (d) application of patient narratives as a means of mind renewal leading to spiritual transformation.

Alla Metamorphousthe te Anakainosei Tou Nous

Alla

Alla is used to indicate a reversal of thought (Alla, 2007). The thought process is moving from a negative (do not be conformed) to a positive (but be transformed). The contrast of the two thoughts is immediately sensed by most Christians; there is remembrance of the way life used to be, identification with the way life is, and acknowledgement of the reason for the transformation.

Metamorphousthe

Metamorphousthe is passive voice, present tense and imperative mood (Romans 12:2, 2007). The passive voice is indicative of the subject of transformation being acted upon or its having received the action expressed, that is, transformation. "No volition - nor even necessarily awareness of the action - is implied on the part of the subject. That is, the subject may or may not be aware, its volition may or may not be involved." (Voice, 2007) The source of the action that is received is generally viewed as the Holy Spirit as described in 2 Cor 3:18: "And we, who with unveiled faces all reflect the Lord's glory, are being transformed into his likeness with ever-increasing glory, which comes from the Lord, who is the Spirit."

Present tense signifies that transformation is not just a one time event in the life of the believer, but it is continuously occurring. The imperative mood suggests responsibility from the one who is the recipient of the transformation. The imperative mood is a command to the recipient of the transformation, telling the recipient to be transformed by renewing his/her mind. Thus the object of the transformation gives permission to the outside force (Holy Spirit) to proceed and accomplish the gradual continuous change known as transformation. However, spiritual transformation may also occur in a rapid and dramatic fashion, as with Saul on the Damascus road (Acts 22:6-11). The battle for *metamorphousthe* occurs in the mind as Chambers points out in his devotion of December 27th: "Our battles are first won or lost in the secret places of our will in God's presence, never in full view of the world." (1935/1992, p. December 27)

Metamorphoo (Metamorfo, 2007) is derived from a combination of *meta*, "to change" denoting change of place or condition, and *morphe* meaning "to form." *Morphe* has been defined as the external appearance (Kittel, 1964, p. 742), or the shape or form of something (Brown, 1975, p. 705). *Schema* is a synonym of *morphe,* and Paul used it in developing the word "conformed" in the same verse. Both *morphe* and *schema* refer to form or appearance (Brown, 1975, p. 708), but *schema* refers to an appearance that is opposed to reality. ***Schema*** refers to outward appearance, and *morphe* refers to the internal appearance from which the outward is derived (Brown, 1975, p. 708-709; Wuest, 1973, p. 207). Therefore, a practical definition of *morphe* is "…that outward expression proceeding from and being truly representative of one's inward character and nature" (Wuest, 1973, p. 49-50). *Morphe* implies a remodeling or changing into another form (Kittel, 1964, p. 755). The change in form is such that it is noticeable to the senses. The

biblical implication of the use of *morphe* is changing to become like deity (Kittel, 1964, p. 757).

The word *metamorphoo* is used three additional times in the New Testament (Mt 17:12; Mk 9:2; and 2 Cor 3:18) (Romans 12:2, 2007). It is the same word translated as "transfigured" in reference to Christ when His glory shined through His clothing. Peter, John, and James saw Jesus; they saw the real entity on the inside as recorded in Matt 17:2: "And He was transfigured before them; and His face shone like the sun, and His garments became as white as light."

Metamorphoo is translated "transformed" twice and "transfigured" twice. The fundamental thought portrayed by the word is change, changing from one form into another. The change is from Christ the man to Christ the God in Matt 17:2 and from man redeemed to man transformed in Rom 12:2. The basic idea of *metamorphoo* is to be changed into the form of what is one's true nature (Boerner, 1984, p. 8). The remodeled appearance is easily visualized as with the transfiguration of Christ in which "Christ's outward expression changed so that He manifested His glory and radiance which were intrinsically true of His divine nature." (Boerner, 1984, p. 9) Rom 12:2 identifies the believer in like fashion. Our progressive transformation makes us more like Christ (2 Cor 3:18).

A mental image equivalent occurs in the biological world in reference to metamorphosis which is also derived from *metamorphoo*. It is usually easier to equate oneself with the lowly, icky worm, but more difficult to identify with the beautiful monarch flying overhead. The change is not a fluctuating change. It is not a wishy-washy change depending on the company with whom we find ourselves. It is a

permanent change. It is a step upward, although small, toward the lofty butterfly. In analogy with the insect world, metamorphosis causes a different outward appearance and also a change in habits (Metamorphosis, 2007).

Paul is referencing the outward appearance of Christians as well. The inward change has already occurred. Our lifestyle needs to reflect that redemptive change. Paul tells us this is not a one time event like redemption but is a multiplicity of events in sequence to move us toward Christ. Our way of thinking must change to result in transformation. The transformation is not just about behavior that indicates how good we are (that may change with a different set of circumstances and people). It is about one's spirit in unity with the spirit of the Creator.

The potential of the butterfly is present in the worm. When metamorphosis takes place, that which was on the inside is manifest on the outside without reference to what was. Likewise, spiritual transformation or *metamorphoo* is all about the change that takes place allowing for the spirit of God residing in His children to be manifest to the world as Christ's likeness. The world sees a different person. God sees a different person.

Morphoo is about spiritual reality. What is inside the person? This may be why there is so much interest in transformation in the current literature, both sacred and secular (Nash and McLennan, 2001). The church has focused on superficiality of behavior, and the world and churched people do not like that focus. That is why Dallas Willard can say:

> We must flatly say that one of the greatest contemporary barriers to meaningful spiritual formation in Christlikeness is overconfidence in the spiritual efficacy of

> "regular church service," of whatever kind they may be. Though they are vital, they are not enough. It is that simple. (2002, p. 269)

How is this inner redeemed nature manifested outwardly? It is in our daily living. It is more than an outward appearance of attendance at a church service. It is where and how we work, play, and interact with others. It is about how Brother Lawrence has been described as enjoying the presence of God (Brother Lawrence, 1988). It is the result of that daily battle of the wills when the winner of the daily battle is God. Daily, what God has done on the inside must be made manifest and visible on the outside. The Holy Spirit desires to see Christians change.

Anakainosi

Anakainosis is a noun and refers to renewal (Anakainosis, 2007). The word implies a turning from something. It is derived from *anakainoo* which is derived from *ana*, "back" or "again," and *kainoo* "new." *Kaninoo* is derived from *kainos* referring to a renewal or renovation. In the New Testament *kaino*s has a particular meaning, "different from another" (Vine, 1940, p. 278), and refers to the renewed being better than the old (Vine, 1940, p. 447). The end result of renewal is a state that is different than that from which one started. The Christian thinks in a way that was not possible prior to renewal (Lenski, 1936). However, in a spiritually developing individual, that renewed state becomes the baseline of another process of renewal and therefore becomes a continuous process.

The only other use of the noun *anakainosis* is in Tit 3:5: "He saved us, not on the basis of deeds which we have done in righteousness, but according to His mercy, by the

washing of regeneration and renewing by the Holy Spirit." It is used with the thought of renewing to the point of being different and superior (Romans 12:2, 2007). It is a time of revolution of the mind. We are renewed from our pride-centered condition to begin our journey from God's point of view. In Titus there is an initial change of mind. In Romans there is a continual growth with submission to God's will. *Anakainosis* is a uniquely biblical word known only in Christian literature and the Greek Septuagint (LXXX) (Moulton and Milligan, 1950). While the use in Rom 12:2 is about a redeemed person, Tit 3:5 is about the first renewing under the direction of the Holy Spirit.

Anakainosis refers to the supernatural work of God in the life of the believer. Titus 3:5 stresses the continuous operation of God the Spirit. God is operative in bringing about the change He desires. The power to change comes from the indwelling Holy Spirit. The Spirit is always willing to act and is emphasized in Tit 3:5. The willing response of the redeemed in allowing the Holy Spirit to work is emphasized in Rom 12. (Vine, 1940, p. 279)

Nous

Nous refers to the mind with emphasis on reflective intelligence (Nous, 2007). *Nous* is our seat of understanding. It is that part of the human entity providing us with the ability to think. With our nous we can perceive situations, analyze data and interpret emotions. In this verse it is equivalent to the biblical use of the heart. Six of the twenty-four uses in the New Testament occur in Romans, and twenty-one are recorded in Paul's writings (Brown, 1975, p. 126; Moulton and Milligan, 1950, p. 670). When Paul uses the

word it is such that the "implication is always that decision and action will result from the process of thought." (Stacey, 1956, p. 179) Eggleston argues that the word is used in reference to man engaged in practical thought and not just speculative reflective reason and he defines *nous* as "the total inner man viewed from a mental perspective which consciously acts in making practical moral judgments" (Eggleston, 1979). Its original meaning was an "inner sense directed towards an object." (Vine, 1940, p. 122) It is "the mental side of man by which he shows himself to be a feeling, willing, thinking being." (Kittel, 1964, p. 952) Thus, the *nous* of cancer patients is easily included as the object of renewal.

While the meaning of *nous* changed in Greek philosophy and religion, Boerner indicates that:

> …nous retains its broad sense of including both the intellectual ability to reason and understand as well as to feel and will; consequently, Paul's use of this word in Romans 12:2 takes a more holistic view of the mind of man rather than merely the ability to intellectually reason and understand .(Boerner, 1984, p. 12)

The mind is the seat of reflective consciousness (Vine, 1940, p. 69) and as such influences thoughts, emotions, and volitions.

Theological Themes

Work Environment Enhances Spiritual Transformation

The workplace environment of a physician's office, when the physician embraces the concept of every Christian a minister or missionary, is the ideal place to put into practice "transformation by the renewal of the mind" for two reasons. First, as one undergoing transformation, the physician is an example of the benefit of being transformed, and second, the transformed physician can facilitate the transformation of others by providing the environment and material for the renewing of the mind. In the Christian context, a medical office has the potential of becoming a locus of edification providing intellectual, moral, and spiritual encouragement. As such it would exemplify the requirement posited by Stevens (1999, p. 17) that: "The theological task is not only to exegete Scripture but to exegete life, and to do these together." Central to ministry is love and compassion for humankind (Lk 6:36), and where better than a physician's office does the opportunity present itself to minister to the person in a holistic fashion and thus worship God so completely?

Humankind's first work environment, the Garden of Eden, provided a place of physical, mental, and spiritual activity. One activity, working and caring for the garden, afforded nourishment, physical activity, mental activity, and spiritual formation for God's created images. The spiritual transformation referred to in Rom 12:2 indicates that worship is to permeate all aspects of our life, as Paul urged in Rom 12:1:

"Therefore, I urge you, brothers, in view of God's mercy, to offer your bodies as living sacrifices, holy and pleasing to God—this is your spiritual act of worship."

The current renewal in thinking regarding the work/worship paradigm (Nash and McLennan, 2001) is a return to the meaning of the Hebrew *abad*, originally referring to "to work or to make" and later to "to worship." (Abad, 2007) John Paul II strengthened this thought by writing: "Awareness that man's work is a participation in God's activity ought to permeate…the most ordinary everyday activities" (1981, p. 58). A Christian is to love work because it is the vehicle through which life has meaning and purpose; it is the primary vehicle of worship and service. "Just as human activity proceeds from man, so it is ordered towards man. For when a man works he not only alters things and society, he develops himself as well…This kind of growth is of greater value than any external riches which can be garnered…" (Paul, 1981, p. 61) Notice how this description of work also describes the renewing of the mind. Mind renewal and thus transformation may actually occur through our work, and our work is to be an expression of our transformation. We are being transformed through our work to intensify the internal and exclude the external. Thus, human activity "should harmonize with the genuine good of the human race, and allow people as individuals and as members of society to pursue their total vocation and fulfill it." (Paul, 1981, p. 57), and as "…man, created in the image of God, shares by his work in the activity of the Creator…" (Paul, 1981, p. 61)

This thesis proposes to enhance spiritual transformation in the workplace environment of a medical oncology office by using narratives written by patients who have grown spiritually during their diagnosis and treatment of cancer. As such, the

physician may be viewed as a manager of a learning organization that will “provide the enabling conditions for people to lead the most enriching lives they can.” (Senge, 1990, p. 101) Thus, the physician office becomes an organizational vehicle for the expression of the two great commandments with promise. The work environment becomes infused with compassion and commitment.

Suffering as a Catalyst for Transformation

Biblically, suffering is presented as universal and continuous. Job 14:1 states “Man born of woman is of few days and full of trouble.” Trouble may be viewed as any problem that threatens our well being (Collins, 1960, p. 7). Suffering is bi-dimensional including the actual problem as well as our response to that problem. In the context of Rom 12:2, suffering may be viewed as a possible catalyst of renewing the mind of the justified.

The natural response to suffering is anger, denial, resentment, and blame. The wife of Job exhibited a natural response when she remarked to her husband: "Are you still holding on to your integrity? Curse God and die!" (Job 2:9). From Job we learn that God does not cause suffering, but He does allow it. We also learn that God’s children are not immune to suffering, but they are to respond to suffering differently. Suffering is a tool which God can use to bring about Christ-likeness in Christians and in so doing fulfill Rom 8:28.

Paul underwent spiritual transformation and achieved contentment and peace (Phil 4:10-13) in the midst of suffering. However, even with the intense and dramatic

experience on the Damascus road, the contentment and peace did not happen immediately. Paul had been a Christian for almost three decades when he described himself as a wretched or miserable individual (Rom 7:17-24), and another several years passed before his writing of Philippians (Vine, 1940, p. 279). Did suffering play a role in the transformation in Paul's life? Perhaps this is why Paul states "I have learned to be content in all things" which implies a renewing of mind through circumstances.

Jesus God's Son responded to suffering by praying, and he learned obedience, acceptance and submission from what He suffered (Heb 5:7-9). We are to follow His pattern (1 Pet 2:21). For example, one of the characteristics of Christians is that they rejoice in suffering because they know what the result will be (Rom 5:3-5). Christians also share in His glory (Rom 8:16-17) and fellowship (Phil 3:10-11) when they suffer. James instructs us to have joy in trials because of the end result (Jam 1:2-4).

On a more modern note, in his sermons, Claypool, who preached in reference to his daughter's diagnosis and eventual death from leukemia, was eventually able to say:

> …if we are willing, the experience of grief can deepen and widen our ability to participate in life. We can become more grateful for the gifts we have been given, more open-handed in our handling of the events of life, more sensitive to the whole mysteries of life, and more trusting in our adventure with God. (1995, p. 97)

Suffering occurs because of natural laws or because of poor decisions or a combination of both. God set in motion the universe and all the physical laws. God has also set in motion laws of relationship and behavior. For example, we know that cigarette smoking causes cancer, yet people make a decision to smoke. God does not

cause a specific patient to get lung cancer, even though 10-15% of patients believe illnesses are a punishment from God (Bauer, 2007; Landrine and Klonoff, 1994; Sorajjakool and Seyle, 2005; Klonoff and Landrine, 1994). A person develops cancer or other illness in response to the laws governing health. The spiritual law says that an event such as cancer may be used by God to bring about the state He desires in us. Is suffering part of a natural law that God uses to get our attention? Lewis (1940/1996, p. 91) remarked that "…pain insists on being attended to. God whispers to us in our pleasures, speaks to us in our conscience, but shouts in our pains: it is His megaphone to rouse a deaf world." Lewis went beyond academic exercises with the death of his wife and shares his emotions as he traveled from despair to acceptance and was able to see pain as a useful tool by God (Lewis 1961/2001; Attenborough, 1993). In the film Shadowlands Lewis concludes:

> Why love if losing hurts so much? I have no answers any more. Only the life I have lived. Twice in that life I've been given the choice: as a boy and as a man. The boy chose safety, the man chose suffering. The pain now is part of the happiness then. That's the deal. (Shadowlands, 2007)

The dominance of self causes one to ask WHY ME? Job complained to God about "why," but God never answered. Kushner asked the same question and eventually concluded God is not all powerful (1981). Billy Graham, in his address at the Episcopal National Cathedral delivered 14 September 2001, addressed the question of why God allows tragedy and suffering "I have to confess that I really do not know the answer totally, even to my satisfaction. I have to accept by faith that God is sovereign, and He's a God of love and mercy and compassion in the midst of suffering." (Graham, 2007)

Often it is only after suffering that we can understand and accept not asking "Why." The New Testament has many references to the fact that we will suffer. Because we strive for comfort (James 4), we are blinded to the way God uses suffering in our lives. The culture of contemporary society is such that we have difficulty accepting suffering as a tool in the hands of a merciful God because our culture is intolerant to discomfort. The question that can be answered is: "Now that this has happened to me what do I do?" This thesis will address the "what" of the matter.

Transformation as a Cooperative Endeavor

According to Rom 12:2 transformation is the desired outcome for our life. Christ is being formed in Christians (Gal 4:19). Since we lost spiritually at the fall, a restoration toward pre-Eden experiences must also be spiritual in nature. Transformation is to be a practical experience rather than be limited to an exegetical exercise. God's desire is that all aspects of life become worship (Rom 12:1). Transformation is associated with a different attitude toward meaning and purpose in life. We are being transformed in the likeness of Christ: " And we, who with unveiled faces all reflect the Lord's glory, are being transformed into his likeness of Christ." (2 Cor 3:18) "Ever-increasing" and "renewal" carry the same thought; that is, it is not instantaneous but gradual with a continuous movement toward the glory. Being like Jesus implies taking on his attitude as recorded in Phil 2:5-11.

Thus, renewal leading to transformation involves a willingness to change. What influences this willingness to change? Mind renewal is a "radical ontological

restructuring of a believer's thought patterns and structures (not merely content), and the consequent altered volitional and behavioral patterns." (Anapach, 1986, p. 42) The volitional aspect of transformation is the part that comes into play in the environment of this study. There is the decision by the physician to provide the environment, the decision by the patient to participate in a study, and the eventual decision to allow the Holy Spirit to work as He so chooses.

Transformation occurs when the Holy Spirit, indwelling in every redeemed individual, is allowed to act by our volition as the supernatural source of renewal (Vine, 1940, p. 279). Thus, we become co-creators with God, and the theme of workplace Christianity occurs again.

Mind Renewal using Patient Narratives

A renewing of the mind implies that the mind is in a state that needs renewal. The world has established patterns of thought and thinking in relationship to all aspects of living, especially in the arena of health, comfort, and self-centeredness. It is widely recognized that thoughts are related to behavior (Hill, 1960), a restatement of the thoughts of the writer of Proverbs (Prov 23:7a).

Crabb, a Christian psychologist, developed a model for changing negative feelings and behavior into positive feelings and behavior. In his model the critical step involves changing through correct teaching.

In this model, the crucial step involves changing the client's thinking, renewing his mind. If it is true that our thought processes (what we fill our minds with)

> largely determine how we behave and what we feel, we must devote considerable attention to his whole matter of wrong thinking. (Crabb, 1975, p. 47)

This thesis is based on the hypothesis that peer-patient narratives will be a good source for teaching positive thinking. However, this approach is more than cognitive therapy which fails to recognize the activity of the Holy Spirit. Patient narratives actually make use of the Holy Spirit. The legitimacy of the peer patient narratives must be evaluated as appropriate based on the expressed beliefs consistent with scripture. While this represents a subjective evaluation by the author, the author choose these for the following reasons: (a) the narratives were consistent with general Christian principles; (b) the narratives were not denominational specific; (c) the narratives were representative of cancer types and gender equality; and (d) the authors knowledge of patients' life was indicative of a transformation. The patients writing the narratives have experienced the transformation; they have written what the Holy Spirit has willed in their lives. The attitude is more than positive thinking or cognitive therapy since the attitude is of divine origin. The divine attitude reorients the will (Ladd, 1974, p. 535). The narrative is written by a patient who has experienced the working of the Holy Spirit in his/her own mind renewal. Thus, the Spirit and word of God are included.

Biblically, two important overlapping effects happen essentially simultaneously for mind renewal. The mind must be exposed to Christ-exalting truth. In this research project exposure to the truth of transformation will be provided via narratives of patients written in their language, having undergone transformation (2 Cor 4:4).

Secondly, the mind must be receptive to the truth. Suffering may be a catalyst simply by helping us to be receptive to the Christ-exalting truth.

Renewal of the mind is more than knowledge of facts or changing one's opinions (Scott, 1972, p. 40). Renewing the mind involves making the mind over (Lutz)—"Christ becomes the center of our thoughts, speech, and life." (Lutz, 1957, p. 11) Barnhouse equates mind renewal to a total preoccupation with Christ in the inner man (1964).

Renewal of the mind of cancer patients is a necessity. It is important to live as well as you can as you live as long as you can.

CHAPTER III

LITERATURE SURVEY

The doorstep to the temple of wisdom is knowledge of our own ignorance.—C. H. Spurgeon (Williams, 2005, p. 288)

Historical Aspects

Definition of Key Words

Although religion and spirituality cannot be totally separated, either by definition or by practice, and although there is more agreement on the necessity to distinguish between the two than on the actual definition, a few examples will be provided for review. For the sake of uniformity, the term "spirituality" is used to include both spirituality and religion unless a distinction is required.

Religion is frequently defined as "a specific set of beliefs and practices associated with a recognized religion or denomination" (Spirituality and Cancer, 2006). The term "religion" may also refer to a lifestyle, such as that of the Amish or the Mennonites. If religion is viewed as culture specific, then it may be viewed as the culturally determined

approach to spirituality. As such, religion is associated with spirituality and becomes the means of expression of that spirituality in a particular culture. The substantive and functional traditions of religion were combined in a definition by Pargament (1997, p. 32) "a process, *a search for significance in ways related to the sacred*." A model for describing spirituality along six dimensions of life was developed by Lapierre (1994). The dimensions included: the journey, transcendence, community, religion, the mystery of creation, and transformation.

Spirituality emphasizes the individual and is not necessarily associated with activity in organized religion, and is often viewed as: "generally recognized as encompassing experiential aspects, whether related to engaging in religious practices or to acknowledging a general sense of peace and connectedness." (Spirituality and Cancer , 2006) Maugans (1996) defined spirituality as "…a belief system focusing on intangible elements that impart vitality and meaning to life's events." Others do not consider spirituality as encompassing a belief system (Ghabi, 2007). Spirituality is found in all cultures and involves a search for meaning and purpose in life, and the search is often through religion (Association of American Medical Colleges, 1999, p. 24-29). Therefore, spirituality is universal, not culturally determined, and it is experienced individually. The author views spirituality as a power greater than oneself (whom he defines as God) that gives meaning and purpose to the process of living (from birth to after death).

Spiritual experiences may be routine as described by Brother Lawrence (Brother Lawrence, 1988) or spectacular as described by Bill Wilson (Alcoholics Anonymous, 1976, p. 11-12). The spiritual experience, is each instance, was transformative. James refers to spiritual transformation as:

> Our ordinary alterations of character, as we pass from one of our aims to another, are not commonly called transformations, because each of them is so rapidly succeeded by another in the reverse direction…but whenever one aim grows so stable as to expel definitively its previous rivals from the individual's life, we tend to speak of the phenomenon, and perhaps to wonder at it, as a 'transformation.' (James, 1902/1994, p. 24)

Katz (2004, p. 5) as part of the Spiritual Transformation Scientific Research Program defined spiritual transformation as: "dramatic changes in world and self views, purposes, religious beliefs, attitudes, and behavior. These changes are often linked to discrete experiences that can occur gradually or over relatively short periods of time." A verifiable definition of spiritual transformation would be the following: "That experience which (a) a person labels as transforming, (b) is framed linguistically as spiritual in nature, and (c) has resulted in lasting behavioral change." (Dureck, 2004, p. 16)

Spiritual distress is common. Although it may be viewed as the negative of spiritual transformation, it may also be viewed on the continuum of spiritual transformation. However, unless intervention occurs it may have a continuously increasing negative effect. For example, a patient may view an illness as punishment from God. The question, "Why me?" is a form of spiritual distress that most individuals experience and appear to work through on their spiritual journey. Patients may also suffer from lose of faith (Pargament, 1997). Most individuals experience a transient amount of distress and only a small percentage develop an obsession with such issues. Higher levels of spiritual distress are identified with poorer health outcomes (Pargament,

2001). Spiritual distress can be measured (Pargament, 1997) and a Spiritual Transformation Scale has been developed that assesses both spiritual growth and spiritual decline (Cole et al. 2006).

Relationship of Healthcare and Spirituality

For much of recorded history health and spirituality have been intimately connected. Major events in the historical timeline of spirituality/religion, science and healthcare have been detailed previously (Goldin, 1994; Koenig, McCullough, and Larson, 2001; Byzantine Medicine, 2006). From the Judeo-Christian perspective, Judaism, thousands of years ago, presented the first relationship between religious prescriptions/proscriptions and healthier living (Gen 17:12; Exod 15:26), and the scientific basis and implications of these commandments have been described in detail (McMillin, 1963; McMillen and Stern, 2000). The use of medicines in association with God's promised healing is seen in the application of the poultice to the boils of Hezekiah (2 Kings 20:4-7; Isa 38:21). In the New Testament, outside the gospels, the only mention of healthcare and church officials is one in which the medicinal value of oil is associated with prayer (Jam 5:14). Christianity, largely based on the commands recorded in Matt 25:35-46, emphasized caring for the sick, whether Christian or not, and played a major role in establishing hospitals primarily to care for the sick (Ferngren, 1992). For over three thousand years the spiritual and physical needs of individuals were juxtaposed under the responsibility of the physician/priest. Even the greatest percentage of the New Testament (by words) was written by a physician.

In the thirteenth century the church, responding to increasing time of the physician/priest being spent on health issues rather than ecclesiastical duties, began strongly encouraging a separation of obligations between priest (theological matters) and laity (medicine and surgery) (Koenig et al. 2001, p. 35). Although, the priestly hierarchy has remained into the twentieth century, it has been increasingly challenged since the antisacerdotalistic nature of Luther's thesis initiated a reclaiming of the priesthood of all believers (1 Pet 2:9).

Scientists, influenced by Thomas Aquinas, often saw their investigations of nature (human reasoning) as discovering God's natural laws. For example, Paracelsus (1493-1541), known as the Luther of Medicine, stated; "The art of healing comes from nature, not from the physician. Therefore the physician must start from nature, with an open mind." (Paracelsus, 2006) He also stated: "For it is not God's design that the remedies should exist for us, ready-made, boiled and salted, but that we should boil them ourselves, and it pleases Him that we boil them and learn in the process, that we train ourselves in this art and are not idle on earth, but labour in daily toil." (Paracelsus, 2006) The motto of Ambroise Pare (1517-1590), as inscribed above his chair in the Collège de St-Cosme, reads: "Je le pansay et Dieu le guarist" ("I treated him, but God healed him.") (Pare, 2006) Leeuwenhoek (1632-1723), the first to describe microorganisms regarded the study of nature as "The work to the glory of God and the benefit of Man." (Leewenhoek, 2006)

Yet, within a few years the Renaissance (1450-1600) birthed an apparent total compartmentalization of humankind between the secular and the sacred. Eventually, the mind was studied by psychology, the body by medicine and surgery, and the spirit was

eliminated from science. Francis Bacon (1561-1626) emphasized scientific methodology and paved the way to eliminate church authority and dogma from scientific endeavors (Koenig et al. 2001, p. 39). The widespread abuses of the church played a major role in both the Protestant and the scientific reformation.

The divergence of healthcare and matters of religion/spirituality/faith continued into the twentieth century; more so in academia than in the everyday lives of people. However, of more recent note, humankind has witnessed a resurgence of the treatment of the whole person (mind, body, and spirit). There is a movement away from the traditionally held view that healthcare providers should be discouraged from spiritual integration in clinical surroundings. Resurgence of interest in spirituality and health in general, and cancer in particular (Weaver and Flannelly, 2004), is due to: (a) continued increase number of published patient stories; (b) widespread acknowledgement of the importance of spirituality in people's lives (Ellis and Campbell, 2004); (c) acceptance that spirituality is subject to investigation without attacking the concept of God or diluting the rigors of science (Hamdy, 2005); (d) increasing number of studies demonstrated an efficacy of religion/spirituality (Koenig et al. 2001; Koenig, 2002); (e) recent recommendations from national accrediting agencies (Joint Commission on Accreditation of Healthcare Organizations (JCAHO), 2006); (f) portraying of religion in a more positive light by the entertainment industry (Testerman, 1997); (g) a religious/spiritual book, *The Purpose Driven Life,* is the best-selling hardback book of all times in America (Rick Warren, 2005) and books on spiritual topics are increasingly bestsellers (Testerman, 1997); (g) an increase in conferences related to spirituality and medicine and continuing education credits for healthcare providers (McCormick, 1998;

Poehlman, 2004); and (h) more rigorous research efforts (Larson and Larson, 2003; Koenig, 2006). Thus, the question is no longer about the reality of health benefits related to faith and spirituality, but is more about the mechanism of how spirituality influences the health and well-being of individuals and how evidence-based medicine should be used in the clinical setting.

The renewed interest is evident in medical school education which is now addressing this deficiency of the role of spirituality (Puchalski and Romer, 2000). In a recent survey sixty-four percent of the medical schools included studies of this nature (Brokaw, Tunnicliff, Raess, and Saxon, 2002), up from thirteen percent in 1994 (Puchalski and Larson, 1998). In reaction to the usual objections as to why physicians should not address spiritual issues, a multi-stage model has been developed in which the clinician can relate to patients at a level consistent with their knowledge, skills and actions (Gordon and Mitchell, 2004). There is a continued growing awareness of the importance of spirituality/religiousness in coping and/or adjusting to illness (Pargament, 1997; Koenig, 2002; Koenig et al. 2001) and to trauma (Linley, 2003; Almedom, 2005).

Importance of Spirituality/Religion in Healthcare

Religion and/or spirituality are important to the majority of people in America, and the importance increases with health problems (Benjamins, 2004). National surveys are consistent in this finding. In a fifty year survey published in 1985, 95% of North Americans believe in God and 84% stated that religion was important in their lives (Gallup, 1985). In most surveys about 90 percent of Americans believe in God (Gallup,

1996; Blanton, 2004), and in a recent survey 62% considered themselves deeply spiritual (Barna, 2005). About 80 percent of patients pray during crises such as illness and the majority expects the prayers to be answered (Gallup and Linday, 1999). Approximately 44% attend weekly religious services (Robinson, 2006). The results are even higher in the Southeastern part of the United States (Gallup and Linday, 1999). The religious involvement by Americans has not changed significantly over the last 70 years (Gallup and Linday, 1999). Family physicians were survey in the Northeast and found that 91% of the patients, compared with 64% of physicians, believed in God (Maugans and Wadland, 1991). The first national study of spiritual transformation has just been published and the incidence of religious or spiritual change in the general population was reported at about 50% and included being "born-again" or another experience that resulted in a changed life (Smith, 2006).

Individuals suffering from various illnesses and traumatic events frequently use spirituality/religion as a means of dealing (coping) with the process/event. King and Bushwick (1994) surveyed hospital inpatients and reported that 77% wanted their physicians to consider their spiritual needs and 37% desired the physician to discuss religious beliefs more frequently. In a pilot study of African-American men with prostate cancer reported that most had actually discussed spiritual/religious beliefs with their physicians and that the patients wished their doctors and clergy would be in contact with each other. (Bowie, Sydnor, and Granot, 2003). Religious coping is often listed as the most important factor to the hospitalized older patient (Koenig, 1998).

The centrality of spiritual transformation to the world's religions is sufficient justification for the study of the phenomenon. Templeton (2004, p. 40) is referenced as

saying: “Throughout history and in our own time, humans have had profound experiences with a spiritual dimension of reality. In all traditions, individuals testify and their lives are no longer the same in the aftermath of these experiences—that they have been transformed.” A transformed or changed life, by definition, should be amenable to investigation by study of the behaviors and/or attitudes resulting from the changed life.

The data demonstrating that patients’ psychosocial, spiritual and cultural values affect how they respond to care is sufficient enough that the Joint Commission on Accreditation of Healthcare Organizations (Comprehensive Accreditation Manual for Hospitals (CAMH), 2003), in addressing the spiritual and emotional needs of patients, stated that patients’ “psychosocial, spiritual, and cultural values affect how they respond to their care.” (CAMH, 2003) The JCAHO has mandated:

> The emotional and spiritual experience of hospitalization remains a prime opportunity for QI [Quality Improvement]. Suggestions for improvement include the immediate availability of resources, appropriate referrals to chaplains or leaders in the religious community, a team dedicated to evaluating and improving the emotional and spiritual care experience, and standardized elicitation and meeting of emotional and spiritual needs. Survey data suggested a focus on response to concerns/complaints, treatment decision making, and staff sensitivity. (JCAHO, 2006)

The separation of the priest’s and physician’s functions described earlier is being challenged on both fronts. Clergy have been involved in healthcare as mental health counselors for many years (Weaver, 2005). Physicians, if they chose, have opportunity

to be involved in the spiritual life of patients (Smalligan, 2005). This is even more so if the physician is spiritually minded as well and raises issues related to appropriate clinical decision-making by the physician in cases of opposing religious views (Hines, 2005). The difficulty in the future is to determine what extent of involvement is acceptable to the physician and the patient.

Other benefits of religious/spiritual activity include: (a) decreased suicide (Dervic et al. 2004); (b) decreased incidence of depression and increased recovery from depression (Koenig et al. 1992); (c) decreased psychological distress in young adults (Salzman, Brown, Brechting, and Carlson, 2005); (d) improved health through lifestyle, social support and means of coping (Oman, Kurata, Strawbridge, and Cohen, 2002); (e) mixed results with prayer or noetic intervention (Krucoff, 2005); (f) decreased substance abuse (Hadaway, Elifson, and Peterson, 1984); (g) improved surgical outcome (Onan, Kurata, Strawbridge, and Cohen, 2002); and (h) others (Olive, 2004).

There is inconsistency between what patients desire that physicians do and what physicians do. There can be no doubt that, for the majority of patients, spirituality/religion is important. Approximately 75 percent of patients would prefer to have their spiritual issues discussed as a part of their medical care (King and Bushwick, 1994), but less than 20 percent of physicians currently discuss such issues with patients (Maugans and Wadland, 1991). The percentage of patients desiring discussion with their physician increased in proportion to the illness severity. For example, it was 33% for those contacts with a routine office visit and jumped to 70% for dying patients. Interestingly, as the intensity of the spiritual interaction increased the percentage of patients desiring that level decreased (MacLean, 2003); possibly indicating that the

routine office visit may not be designed for optimum spiritual dialog between physician and patient.

This incongruity will likely change since spirituality and healthcare are now being addressed during medical training (Puchalski and Romer, 2000). Recently a four-stage model was developed to deliver spiritual and religious care consistent with the competence of the healthcare provider (Gordon and Mitchell, 2004), and a brief spiritual intervention was shown to have a positive effect on patient perception of care and well-being, even with physicians of different religious backgrounds (Kristeller, Rhodes, Cripe, and Sheets, 2005).

Recognition of the importance of spirituality in cancer care is occurring at the national level as evidenced by a recent statement from the National Cancer Institute: "Given the importance of religion and spirituality to patients, integrating systematic assessment of such needs into medical care, including outpatient care, is crucial." (Spirituality and Cancer, 2006) Although there is much disagreement about when such matters should be addressed with the patient and family--and it is often considered an end-of-life issue rather than an issue at time of diagnosis (Murray, Kendall, Boyd, Worth, and Benton, 2004)--the NCI paper goes on to state: "Acknowledging the importance of these concerns and addressing them, even briefly, at diagnosis may facilitate better adjustment throughout the course of treatment and create a context for richer dialogue later in the illness." If spirituality/religious adjustment and coping improve quality of life in cancer patients it seems intuitive to begin such adjustment/coping as early in the diagnosis as possible. The Joint Commission of Accreditation of Healthcare Organization now requires spiritual assessment on each hospitalized patient (CAMH, 2003). Failure to

acknowledge, intervene or refer patients, when information is sufficient for evidence-based medicine, is equivalent to malpractice whether dealing with the efficacy of an antibiotic or the benefits of spiritual interventions.

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Current State of Spirituality and Cancer Care

The Cancer Problem

CANCER! The word is spoken sympathetically and is often whispered. Cancer is one of the most dreaded of diseases. When a person faces a life-threatening diagnosis of cancer it produces an intense crisis. The news of having cancer often results in strong emotions such as fear, hopelessness, helplessness, and anxiety. The patient experiences extreme vulnerability to the disease, to unfamiliar technology, and the healthcare delivery system. Life-long plans change overnight. The diagnosis of cancer confronts every dimension of living. The life-threatening nature of cancer predisposes one to an increased awareness of one's meaning and purpose of life and often brings spiritual matters to the forefront. Can such a crisis serve as a catalyst for spiritual growth?

There have been great advances in cancer care in the last few decades. For cancer diagnosed between 1995 and 2001 (the latest data), the five year survival mark is greater than 65% (compared to 50% between 1974 and 1976) (Cancer Facts and Figures, 2005). Cancer is actually the most curable of all chronic illnesses (since the majority of chronic illnesses can only be treated and not cured, for example hypertension, diabetes, lipid disorders). However, it remains a feared illness. Approximately 1,300,000 cases of cancer

are diagnosed annually (Cancer Facts and Figures, 2005). Cancer is the second leading cause of death in the United States, resulting in one out of four who die each year, or over 500,000 deaths. (Cancer Facts and Figures, 2005) The advances have dealt with the physical reality of cancer and the development of new drugs that was fostered by the development of the National Cancer Institute in 1937 and the National Cancer Act of1971. The emotional care of patients has lagged behind the physical care. Even behind the emotional care is the spiritual care. Although emotional well-being has been considered part of the model of health care for some time, the role of spirituality is just coming into the light. During the past few years it is becoming more widely accepted that spiritual care is a subject worthy of investigation.

Anecdotal Evidence

There exists a paucity of scientific or religious studies that have prospectively investigated spiritual changes (transformation) in general and even less so in patients with the diagnosis of cancer. Numerous empiric studies demonstrate the importance of spirituality/religion in adjustment to sickness in general and cancer in particular.

Patients have made statements about spiritual growth during the course of their treatment (Daugherty, 2006). Some individuals were religious prior to a stated spiritual transformation, and others would not be considered so. The spiritual changes sometimes occurred as quantum jumps and at other times more gradually. Regardless, the patients viewed themselves in a new and better spiritual situation, often focusing, not on their healing, but on glorifying God.

For example, a young lady with lymphoma stated a few weeks before her death: “Having cancer has allowed me to have a relationship with God that I’m not sure I have had without it. It may sound strange to say I feel like a ‘chosen’ one, but I do. I feel more content and blessed now than ever before.”

A gentleman with widespread prostate cancer declared: “Cancer is the best thing that ever happened to me.” When I inquired how this could be he explained: “Since being diagnosed with cancer I have been used by God to lead more people to Christ than I ever thought about. My life has taken on a new meaning.”

A young man with metastatic testicular cancer was able to say: “I can now honestly say I am thankful for what cancer did and helped produce in my life.” He is currently pastor of a large church in Alabama.

Another patient, when asked what she would have me tell a group of college students to whom I was going to speak said: “Don’t be a wimp for Jesus.” She went on to explain how when she was first diagnosed with ovarian cancer that she prayed for healing and solicited the same from all her friends and from area churches. As time progressed she realized that should not be her request. Instead, she should pray that whatever happens to her she will be able to glorify God.

This sense of blessedness was echoed by a mother with breast cancer: “We are blessed through our trials in life. It is truly amazing how God can use them to teach us to grow and improve. I have gained so much from my illness.”

Thankfulness was expressed by a patient with colon cancer: “I am thankful that He allowed me this experience for several reasons. First, it taught me to trust Him completely. Second, it taught me to love others as Christ loves us—unconditionally.

Third, it taught me compassion. This is a reason that has really touched my life and made it better. I see people differently than I used to."

Published Narratives

In addition to anecdotal patient stories, the narratives of cancer patients are a great source of information about spiritual transformations. They provide hope for countless individuals struggling with cancer and these narratives are also a great source of anecdotal information about spiritual struggles and spiritual transformation. Such testimonials often deal with how to survive cancer, examples of spiritual transformation are found within their covers.

To mention a few: "Life is a gift—one more truly appreciated by those who have faced a diagnosis of cancer. Did you wake up this morning and embrace the day? I did, and it's something that cancer taught me to do." (Clifford, 2002, p. 126)

"Cancer has changed me in many ways. My whole outlook on life is so much clearer now…I appreciate my life so much more now that I have had cancer." (Stoliker, 1996, p. 34)

"Illness allows me the opportunity to examine my life because it changed so many things I have taken for granted…I choose to accept the blessings that illness offers rather than focus on the problems that are out of my control." (Hammond, 2003, p. 22)

"Facing the possibility of death brought an instant and intense focus to my life." (Burkett, 1996, p. 89) "I have never asked God *why* this happened. It really doesn't matter *why*. Instead, I have asked *what* God would have me to do as a result of having

cancer." (Burkett, 1998, p. 11) Just before his death he was able to write: "Your attitude is very important. Since no one is going to live forever, what you strive to do is live as long as you can in reasonably good health—without fear. The more you worry, the greater the probability that you will not live as long as you could. Worry affects your spiritual well-being, as well as your immune system and your entire body." (Burkett, 2003, p. 25)

"God will bring blessing through your trial because you matter greatly to Him and He longs to show you that. He may bless you with physical healing, or He may bless you by healing you emotionally of some deep-seated hurts. He may bless you spiritually with the joy of knowing Him in a way you have never known before. Or He may bless others through you in unimaginable ways." (Eib, 2002, p. 9)

Do the stories represent the tip of the proverbial iceberg or do they represent the majority of such events? It is not possible from testimonials, published narratives or the few scientific studies done to know the incidence and duration of spiritual change. The recently published national spiritual transformation study reported that the main cause of such change was normal religious activity, but a serious personal problem involving illness, accident or death, accounted for about one-fourth of all cases (Smith, 2006). A diagnosis of cancer certainly falls within the category of a serious personal problem. However, many questions remain unanswered in general and details remain lacking in specific in reference to persons diagnosed with cancer. The proposed study will provide considerable information in that the study will be prospective; cohort-controlled and provide quantitated data.

Not everyone is capable of writing or even telling his or her story. Some patients have no desire to tell their story, and others may lack the ability to do so. A review of published narratives stories does not provide an indication of the number of spiritual transforming events. The thesis will investigate all patients that present for treatment of cancer and give informed consent and will determine the incidence of spiritual transformation in the setting of an outpatient medical oncology office in Northwest Alabama.

Scientific Studies

Can spiritual change (transformation) be studied? The separation of natural science and religion over the last couple hundred years is being challenged with the desire for a more systematic and analytic approach. Study of the efficacy of religion/spirituality, as it moves from the subjective and oftentimes sensational, must demand the implementation of the foundations of the scientific method—reproducibility and accuracy (Hamdy, 2005). At the same time, application of the scientific method to the results, does not and can not address the mystery of the process, but must acknowledge the reality of the mysterious.

A relation between religion and health is often demonstrated by epidemiological studies. Such studies are based on religious involvement and/or frequency of attendance of religious gatherings. Although such studies allow for quantitation of religious activity they do not necessarily address spiritual change. Involvement in activities generally thought to be occurring in a religious ethos, while not associated with attending religious

services, needs to be examined, including prayer, meditation, service to others, forgiveness, etc. This study will address this by using measures of spiritual transformation.

Results of spiritual transformation can be studied. If spiritual transformation is to be examined scientifically it must be quantified. To date this has largely been lacking but various measures of spirituality and religiosity have been reviewed by Hill and Hood (1999). The Spiritual Transformation Inventory (STI) by Hall (2006) was developed based on multidimensional measures, with the intent of having an assessment tool for individuals that could be used by educators, counselors, pastors, social workers and therapists. The goal of Cole (2004) was to develop a spiritual transformation scale for cancer patients and it was subsequently shown to provide measurement of spiritual growth and spiritual decline (Cole et al. 2006).

There is no doubt that spirituality/religiosity contributes to the emotional adjustment to cancer and the side effects of treatment for both the patient and to caregivers (Holland, 1999; Brady, 1999). Patients who cope religiously have less discomfort, reduced hostility, less anxiety and less social isolation (Acklin, Brown, and Mauger, 1983; Kaczorowski, 1989; McCollough, 2000). Other studies have demonstrated that characteristics often associated with strong religious beliefs, such as hope, optimism, freedom from regret, and life satisfaction have been shown to be associated with improved adjustment in cancer patients (Weisman and Worden, 1976-77; Pargament, 1997; Laubmeier, Zakowski, and Blair, 2004) reported that spirituality was associated with less distress and better quality of life in patients diagnosed with cancer within the last five years. The spiritual well-being of patients, especially a sense of

meaning and peace, is associated with improved quality of life in spite of increased fatigue and pain (Brady, 1999), as well as a decreased level of depression (Nelson, 2002). Interestingly, religiousness was not related to the level of depression (Nelson, 2002). Breast cancer survivors were found to have increased personal growth when they relied on spiritual resources (Carpenter, Brockopp, and Andrykowski, 1999). At the same time women with early-stage breast cancer who experience spiritual struggles have a lower quality of life (Manning-Walsh, 2005). From a Christian perspective struggles should result in a more hopeful life (Rom 5:1-5). Oftentimes studies are referring to the quality of life during the struggle and not afterwards. Religiousness is not related to the use of humor as a means of coping (Saroglou, 2002). Faith-based communities are an important source of health program promotion among older adults (Roff et al. 2005).

The role of prayer is difficult to study. While prayer is seen as an adaptive tool (Halstead and Fernsler, 1994), concerns about praying are a source of spiritual distress in up to 30% of the patients (Taylor, Outlaw, Bernardo, and Roy, 1999). For a discussion on the use of prayer by cancer patients and how clinicians might conceptualize prayer see Taylor and Outlaw (2002). A recent meta-analysis showed religious involvement and spirituality to be associated with better health and longer life expectancy (Mueller, Plevak, and Rummans 2001). The immune status of patients with metastatic breast cancer was higher in women who reported increased spirituality (Sephton, 2001), and in those with higher attendance at religious services (Koenig et al. 2001). The relationship between religious distress and negative healthiness has been shown by some (Koenig, Pargament, and Nielsen, 1998; Pargament, 2001) and questioned by others (Sloan, Bagiella, and VandeCreek, 2000). Meta-analysis of 42 different studies and the mortality

levels in patients with religious involvement versus without were examined. Those with religious involvement showed lower mortality and the difference was more pronounced with women. Rompmdetta and Sills (2004) found a 25% decrease in mortality rate for religious services attendees for healthy individuals but found no difference for cancer patient mortality. The benefit of spirituality may be in the quality of life lived and not in the length of the lived life.

Almost no prospective studies have been published. Recently the Spiritual Transformation Scientific Research Program of the Metanexus Institute on Religion and Science began a multi-disciplinary research program. Data coming from this initiative has been presented but not published. This thesis will be the first prospective study of spiritual transformation in a cross cohort controlled setting.

Scientific studies of the spiritual transformation undergone by patients have heretofore been very difficult. Although science and religion are not known for their collaborated efforts, we are witnessing a shift in investigative efforts due to several independent factors: (a) increased awareness of the role of religion and spirituality in people's lives; (b) anecdotal evidence of the benefits of spirituality in the care of patients with various medical problems; (c) realization that while the spiritual realm cannot be investigated the effects of some spiritual phenomenon can be studied; and (d) that spiritual issues can be addressed by physicians in a brief, non-threatening inquiry.

Other investigators have cautioned that the changing of lives by cancer to make one a better person is the exception rather the rule (Merwald, 2002). While it should never be inferred that one must undergo a change and be a different person if they have

cancer, the possibility for growth along each individual's spiritual journey should be optimized by the healthcare providers.

Spirituality is associated with long-term survival in HIV patients (Ironson, Stuetzle, and Fletcher, 2006). She has identified helping others and decreased cortisol as a mechanism for the long-term survival seen in HIV patients experiencing increased spirituality (Ironson et al. 2002).

Awe seems to be associated with spiritual transformation : "Powerful feelings of awe during moments of spiritual, aesthetic, and moral experience seem to prepare the mind and heart to make changes, and these changes seem to be almost always for the good." (Keltner, 2004, p. 19) It is Keltner's hypothesis that emotions related to awe may function in the brain in such a way that it leads to spiritual transformation. The neuro-theology of this suggestion is ripe for experimentation.

There are many issues in research endeavors involving religion and health. These have been discussed in detail previously (Flannelly, Ellison, and Strock, 2004). Several organizations are involved in research and clinical practice. The John Templeton Foundation, established in 1987, listed its purpose as: "to stimulate a high standard of excellence in scholarly understanding which can serve to encourage further worldwide explorations of the moral and spiritual dimensions of the Universe and of the human potential within its ultimate purpose." The foundation is currently funding more than 300 projects. Detailed information is available at the web site (Templeton Organization, 2006).

The Spirituality/Medicine Interface Project is a joint effort by The Southern Medical Association and the Southern Medical Journal, and is funded by the Templeton

Foundation. (Hamdy, 2005). The project will develop three educational programs for healthcare providers and clergy, and the Southern Medical Journal will publish additional material on a quarterly basis developed to the project. Further details are available in at the Southern Medical Journal web site (Spirituality, 2007). The project has already called attention to the need for more quality research in the field of spirituality and health (Hamdy, 2005).

The Metanexus Institute, based in Philadelphia, "advances research, education and outreach on the constructive engagement of science and religion." (*About Metanexus*, 2007) The Spiritual Transformation Scientific Research Program currently funds 24 grant applications looking at various aspects of spiritual transformation. The program has sponsored two symposia to date *(The Spiritual Transformation Scientific Research Program*, 2004; *The 2006 Research Symposium of the Spiritual Transformation Scientific Research Program, 2006).*

The reuniting of spirituality and medicine is truly occurring. Humankind is searching for transcendent meaning, as evidenced by sales of twenty million copies of Purpose Driven Life. Only a few question the salutary effects of spirituality/religions on overall well being. It is left to be seen whether the rigidity of the scientific method be modified by inclusion of the mysterious, the immeasurable, and the spiritual? It is somewhat ironic that both health care and religion are about to be reshaped by the power of the same transformation.

Methods of Clinical Intervention

Today's climate of healthcare is not conducive to increased involvement with patients. Numerous studies suggest an inverse relationship between compassionate patient care and technological advances (Weaver and Ellison, 2005). Because of the increase in overhead and regulatory problems, as reimbursements have been cut repeatedly, the physician must increase the number of patients seen just to maintain status quo. The physician-patient interaction is a fragment of specialized care rather than a holistic approach. This environment dictates, from the physician's point of view, that any intervention be brief. Likewise, patients are very time-conscious, and consideration must be given to restricting intervention to a minimum time, and convenient time.

Arguments for not discussing spiritual issues include the following: (a) lack of time; (b) fear of imposition of beliefs; (c) lack of knowledge; (d) lack of experience; and (e) no spiritual experience (McCormick, 1998). This thesis deals with an intervention that is not overly time- consuming, does not require any training or specialized knowledge on the part of the physician, and, the peer patient narratives are written about a patient's own journey. It just so happens that many times this does involve spiritual issues.

Randomized trials with cancer patients have suggested that support groups benefit survival (Spiegel, Bloom, and Kraemer, 1989; Fawzy, Fawzy, and Hyun, 1993), but the findings have not been confirmed by others (Cunningham, 1998). Support groups may or may not provide an opportunity to raise spiritual concerns. There is little data on the effectiveness of support groups in dealing with spiritual concerns. Targ and Levine

(2002) conducted a randomized controlled trial comparing a mind-body-spirit group to a standard group for women with breast cancer. Spiritual well-being was improved in both groups, but the former showed improved spiritual integration. Longer survival has been demonstrated when patients are engaged in spiritually oriented exercises (Cunningham, 1998; Cunningham et al. 2000). In a recent preliminary report spirituality was integrated into a group psychological therapy program for individuals diagnosed with cancer, and called for further research in this area (Cunningham, 2005).

Spiritually based intervention programs were discussed previously (Harris, Thoresen, and McCullough, 1999). Spiritual intervention for people diagnosed with cancer was studied by Cole and Pargament (1999). A psychotherapy program called *Re-Creating Your Life: During and After Cancer* was developed that involved a weekly 90 minute intervention for six weeks. The study addressed existential concerns (control, identity, relationships and meaning). The results of a pilot study were reported as favorable and expanded in a subsequent publication. (Cole, 2005; Hopkins and Cole, 2005) presented a meeting abstract and discussed spiritual changes in people coping with cancer. Recently a Spiritual Transformation Scale was developed and initial studies demonstrated both spiritual growth and spiritual decline in cancer patients (Cole et al. 2006). Another well designed study investigated the influence of even a brief inquiry by the physician into spirituality has demonstrated patient benefit regardless of the religious beliefs of the physician (Kristeller et al. 2005).

The first reported use of an intervention with spiritual/religious content was recently published in detail (Cole, 2005). Of the thirty-four eligible patients in a spiritually-focused psychotherapy study only sixteen completed the study. This study

involved eight weekly two-hour group sessions (to decrease participant burden the number of sessions was reduced to six for the second group). Eight participants declined participation (scheduling conflicts, decreased interest, and hospitalization); nine provided incomplete data or failed to attend fifty percent of the intervention sessions. Physical and psychological well-being were determined pre-treatment, post-treatment and two months later. The group with spiritually-focused psychotherapy reported a positive impact on pain severity and depression.

Such results point to the necessity of providing intervention that is easy for the healthcare provider and the patient. A limitation of this study is the grouping of individual newly diagnosed or re-diagnosed with cancer and the wide time interval from diagnosis before intervention (two to twenty-four months). The conclusion of this preliminary study was:

> Psychologists clearly have an ethical responsibility to be responsive to the needs of spiritually diverse clients. The development of programs that integrate spiritual issues and resources fulfill that responsibility provided the programs are compatible with the standards of professional care and are ethically sensitive to the spiritual and religious values and beliefs of the participants. (Cole, 2005, p. 224)

In a similar fashion (Pargament et al. 2004) proposed a series of eight psycho-spiritual interventions for individuals suffering from HIV/AIDS. The intervention integrated spirituality into seven areas of concern for women with HIV

The recently reported study showing that a brief five-to-seven minute intervention resulted in positive effects on patient perception of care and well-being (Kristeller et al. 2005) regardless of the religious beliefs of the physician. These findings have important implications in the widespread adoption of spiritual inquiry practices since time constraints are usually one of the prohibitive factors listed.

Storytelling has long been used therapeutically (Rosen, 1982; Lankton and Lankton, 1988; Cox and Albert, 2003). Usually stories are written with the purpose of producing changes in the recipient at the emotional level subsequently causing behavioral change. What better way to provide an emotionally-laden story with cancer patients than to use those written by the patients having experienced the same or similar diagnosis and treatment? To this end, stories were collected and rewritten by the author in such a way to protect anonymity and to keep each narrative to about five minutes. In a recent study participants were randomly assigned to receive a story or psychoeducational information regarding relationships (Parker and Wampler, 2006). The amount of negative affect and negative feelings toward the relationship were equally reduced by both treatments.

Cancer patients frequently complain of fatigue during treatment and any intervention should be designed with this in mind. Since newly diagnosed patients just starting a chemotherapy treatment program are in our office at least weekly, the narrative intervention program was designed around this schedule. The brief intervention was designed not to be a hindrance on the patient, physician and staff. Due to the positive results obtained with a five-to-seven min assessment, we chose to limit the intervention to this time frame. The format of narrative storytelling was chosen since we had a collection of patient stories that had been written over the years. Gender was represented

equally. The narratives were written by former patients and chosen to reflect good results from treatment, and emotional content. All patients who had written narratives were living at the time the study was initiated.

Any method of intervention needs to be conscious of the overall physical, mental and emotional state of the patient as well as the time constraints of each. Little research has been directed at enhance the spirituality of cancer patients. The salubrious effects need to be investigated. The importance of spiritual matters with cancer patients is largely unquestioned, yet studies designed to enhance the spiritual growth of patients or designed to change negative spirituality into positive spirituality are essentially nonexistent. This thesis will approach the deficiency by designing and testing a program to enhance spirituality in patients with cancer using a brief peer patient narrative intervention. Spiritual support often involves the sharing of religious experiences (Krause, 2002), and narratives represent a form of shared religious experience.

CHAPTER IV

PROJECT DESIGN

> Science and religion tend to be viewed as opposite ends of the spectrum, with a great deal of emotional overlay. As a result, scholars have often avoided studying 'spirituality' and 'transforming experiences' the way they study other phenomena. The fact that researchers are now applying contemporary scientific methodologies to understanding beliefs and behaviors is itself a marvelous transformation. (Katz, 2004, p. 5)

Introduction

The protocol is for a prospective study of the effect of peer patient narratives on the spirituality of individuals recently diagnosed with cancer. A peer patient narrative is defined as a story written by a previous cancer patient about his/her experience with cancer, the treatment and side effects. The principal scientific objectives of the study are:

1. To determine if a brief intervention of storytelling based on peer patient narratives results in meaningful improvements in the overall physical, spiritual and psychological well-being.

2. To determine if the storytelling intervention will improve the overall well-being of those individuals showing signs of spiritual distress.

Any selection process whereby patients are randomly assigned to an intervention or no intervention arm (standard care) would not control for the increased time the patient would spend with the staff, and this could be a contributing factor in the overall well-being experienced by the patient. However, the author has two office locations and one office cohort will serve as an intervention using peer patient narratives written from a spiritual perspective and the other as an intervention written from a non-spiritual perspective of factual information. This will control for the bias related to participating in a study, having increased physician and healthcare provider contact and the activity of completing the questionnaires. The use of a narrative at the time of the patient visit will maintain compliance with the study.

The study protocol does not specify treatments or require any particular distribution of patients or require the participating physicians and health care providers to alter their practice patterns. The patients will continue to be treated according to their physician's own best clinical judgment. The principal value of the study lies in its ability to gather data on a well-defined population of patients with known characteristics. The study is designed to collect a highly focused set of data that are believed to be directly relevant to the question of spiritual change.

The Principal Investigator (the author) will sign the appropriate paperwork and will be responsible for assuring that the site and all participating physicians and healthcare workers at the site comply with all requirements and procedures.

Patient Selection

Individuals recently diagnosed with cancer and who are patients at the Northwest Alabama Cancer Center in Florence and Muscle Shoals, Alabama, will be possible participants. Patients must be adults (18 years of age or older) who will be undergoing adjuvant chemotherapy at the Northwest Alabama Cancer Center, within four (4) weeks of surgical resection of the malignancy. Adjuvant chemotherapy is chemotherapy given in association with the complete surgical removal of cancer with the aim of decreasing the chance of cancer recurrence. Prospective patient participants must also meet the following criteria:

1. Patients must have histologically confirmed malignancy that has been surgically removed. That is, the patient will be undergoing chemotherapy in an adjuvant setting.
2. The patient must not be currently participating in any other clinical study involving psychological evaluations that would compete or be in conflict with the current study.
3. If the patient is identified for the study while an inpatient, they must be able to be followed for the duration of the study.

4. The patient must speak and read English and be able to answer the type of simple questions presented in the patient questionnaires.

5. The patient must have an ECOG performance status $\leq$ 2 or a Karnofsky performance status $\geq$ 60% (details of determining these parameters are included in Appendix A).

6. The patient must consent to participate in the study after being fully informed about its goals and procedures, and must document the consent by signing the informed consent form provided (Appendix B).

7. Life expectancy greater than 12 months.

8. Ability to understand English and the willingness to sign and provide a written informed consent document.

Patients will be excluded from consideration as participants if they meet the following criteria:

1. Previous diagnosis of cancer requiring chemotherapy and/or radiotherapy.

2. Uncompensated psychological disorder.

3. Anyone currently under the care of a psychiatrist will require his/her permission to participate in the study.

4. Any comorbidity or condition which, in the opinion of the treating physician or Principle Investigator, that are relevant to the patient understanding, participating in, or completing the study.

5. Clinically significant laboratory abnormalities that might interfere with the ability of the subject to complete the intervention and post-intervention follow-up.

6. Pregnancy or lactation.

Patient Enrollment

Both men and women and members of all races and ethnic groups, and any religious affiliation, who speak and read English, are eligible for this study. The plan for the protocol is to enroll all willing participants for a two month period. This time may be increased if necessary to compensate for patient withdrawal from the study or if enrollment is not sufficient. It is anticipated that each cohort study arm will contain at least ten (10) patients.

Patients will be recruited from the practice sites of Northwest Alabama Cancer Center. In order to participate, patients must be enrolled in the study and must be able to complete baseline data collection prior to beginning chemotherapy treatment. Patients will be invited to participate in the study as they become eligible. Each site will identify and seek to enroll all consecutive patients if eligible, unless the patient's physician is aware of a specific reason where it would be inappropriate to do so. Other than such exceptional cases, the offices should not seek to select eligible patients with particular characteristics for inclusion in or exclusion from the study. The Principal Investigator or designated appointee (Research Nurse) will briefly explain to eligible patients the purpose of the study, emphasizing the confidential and voluntary nature of the patient's participation, and the procedures for participation.

Every effort will be made, within bounds of safety, to have every patient complete the intervention narratives. Patients who have intervention narratives discontinued due to difficulty with the study will have personal counseling available to them to help them

cope with the diagnosis and treatment of the cancer. Patients may be discontinued from the study if:

1. The Principle Investigator recommends and documents the reason.
2. Patient decision to withdraw consent or discontinue for any reason.
3. There is an unacceptable adverse event thought to be related to the study.
4. At the request of the review board.

Any patient who discontinues during the intervention and follow up period will be contacted about a final interview.

Methodology

When individuals are asked of their interest in participating in this study they will be informed that the study is designed to look at physical, emotional and spiritual/religious changes that patients experience as they undergo chemotherapy. The hypothesis is that a simple intervention will have an effect on these changes. If the patients agree to participate then informed consent will be obtained in person. They will be asked to complete the information needed at that time and continue with the intervention narrative. A matrix indicating the data items to be collected and the schedule for each item is included in Appendix C.

Demographic (Appendix D) and clinical (Appendix E) information will also be obtained on each patient as is customary in the practice of medicine. Physical well-being will be assessed with each weekly office visit. Information will be available as to cancer type and stage. Medical information will be available from the patient's medical chart.

Patients will undergo a complete review of symptoms (nausea/vomiting, pain, fatigue/lack of energy and symptoms since last visit) and review of medication changes each week.

The Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS) scale will be used to measure various domains of religiousness/spirituality, including daily spiritual experiences, values/beliefs, forgiveness, private religious practice, religious/spiritual coping, and religious support (Appendix F). This instrument was developed by the National Institute on Aging and the Fetzer Institute, and has been shown to have appropriate reliability and validity scores (Fetzer, 2004).

The Functional Assessment of Cancer Therapy Scale-G (FACT-G) will be used to assess quality of life related to pain, treatment side effects and physical functioning (Webster, Cella, and Yost, 2003) (Appendix G). The FACT-G (now in Version 4) is a 27-item compilation of general questions divided into four primary Quality of Life domains: Physical Well-Being, Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being. It is considered appropriate for use with patients with any form of cancer.

Psychological well-being will be measured using the Center for Epidemiological Studies-Depression (Radloff, 1977) (CES-D; Appendix H). The CES-D is a widely used twenty item instrument to assess depressive symptoms. The scale has good internal reliability and correlates with other measures of depression.

The Positive and Negative Affect Scale (PANAS-X; Appendix I) will assess non-pathological positive and negative affect (Watson and Clark, 1994/1999). Individuals are asked to rate on a five-point scale the extent to which they have experienced a variety of

positive and negative feelings. The subscales' internal consistency and reliability has been high.

The Religious Orientation Scale (ROS) will be used to assess how important religion is to a person (Allport and Ross, 1967) (Appendix J). This instrument measures both extrinsic and intrinsic religious orientation. Internal consistencies for the intrinsic scale range from adequate to excellent and for the extrinsic scale somewhat lower.

The Daily Spiritual Experience Scale (DSES) is a 16-item tool that assesses the relational and affective aspects of spiritual life and provides a good measure of spiritual well-being (Underwood and Teresi, 2002) (Appendix K). This tool has high internal consistency and test-retest reliability.

The Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp-12) (Peterman, Fitchett, Brady, Hernandez, and Cella, 2002) instrument is a12-item Spiritual Well-Being Scale (Appendix L). It is considered appropriate to use with individuals with any chronic illness.

The Spiritual Transformation Scale (STS) is a newly developed instrument to assess spiritual transformation following a diagnosis of cancer (Cole et al. 2006) (Appendix M). It is a 40-item instrument that has been shown to be psychometrically sound and to assess both spiritual growth and spiritual decline.

At the completion of the study each participant will be asked to complete an assessment of the overall study (Appendix N).

The chemotherapy treatment will be administered on an outpatient basis and the intervention narratives will occur during scheduled office visits. During the study the patients will be asked to complete several questionnaires aimed at determining how well

they are coping with the diagnosis of cancer and the treatment and its side effects. Patients will not need to have any additional blood work or any invasive procedures done because of this study. However, patients may need these tests and procedures as part of regular cancer care, but they will not be done more often because you are in this study.

Each patient will be followed through to the completion of the study. This intervention schedule will not be a problem since patients are seen weekly while receiving chemotherapy and followed closely for many years after the diagnosis and treatment of cancer.

Patients will be considered as enrolled in the study when the informed consent is obtained. They will complete a special form that requests identifying information, contact information and basic demographic information. The physician must complete a baseline clinical assessment of each patient enrolled in the study and document the informed consent procedure. All data is to be entered as promptly as possible. The patients' medical records will be maintained indefinitely at the appropriate office locations. The practice site will maintain all source documents required to support he data submitted for each patient for at least two years following competition of data collection at the site.

As one of several clinical outcomes being monitored, adverse event (AE) information will be collected and reported (Appendix O). An AE is defined as any untoward medical occurrence in a clinical-investigation patient that participated in a study and which does not necessarily have a causal relationship with the treatment. An AE can therefore be any unfavorable and unintended sign, symptom or disease temporarily associated with the intervention studied. An AE can be any new, undesirable

medical occurrence or change (worsening) of an existing condition that occurs in a subject during or after treatment, whether or not considered to be product related. The patients will be instructed to call for an adverse event. At each follow up visit the physician will inquire about adverse events. All AE are reported within 24 hours of occurrence.

It will be emphasized that if the patient believes they have been injured because they took part in the study that it is important to tell the study doctor. The patient will be informed that they can tell the doctor in person or call him at (256) 381-1001 or (256) 764-4200. The patient will receive medical treatment if they are injured as a result of taking part in this study. If the patients believe they have been harmed spiritually/religiously an ordained minister/counselor (Drew Jamieson MDiv, MTh) on staff at Northwest Alabama Cancer Center will be available at all times for referral.

Patient Protection

The protocol will be reviewed and approved by the Human Subject Committee of (HSC) of the University of North Alabama. The Principal Investigator is an adjunct faculty member of this institution in Florence, AL, and the co-investigator is associate professor in the department of psychology at the institution. Prior to initiating recruitment or enrollment of patients each office location must have a current HSC approval letter in the study binder located at that office. At the completion of the study the principal investigator will notify the HSC about the study completion.

Each office location must comply with all applicable requirements concerning the privacy of individual patients' protected health information as specified in the Administrative Simplification section of the Health Insurance Portability and Accountability Act (HIPPA) of 1996. Northwest Alabama Cancer Center locations are in complete compliance with HIPPA and compliance adherence is under the supervision and direction of a HIPPA Compliance Committee (Jackie Sharpton, Chairperson, (256) 381-1001).

Prior to initiating recruitment or enrollment of patients, each site must have the individuals involved in the study complete a training session in which the principal investigator will review the protocol and explain the details and all individuals will have an opportunity to ask questions.

All study information is maintained in the source documents (the first place data is recorded). The source documents provide an audit trail to verify the authenticity and accuracy of the data reported in the Case Report Forms (Appendix P).

Informed Consent

Before a patient can be enrolled in the study, informed consent must be obtained and documented by having the patient sign the informed consent form with a witness present. The witness can be a family member or a staff member of Northwest Alabama Cancer Center. The patient's physician or another clinical person must fully explain the purposes, procedures, benefits and risks of the registry to all patients invited to participate, and must answer any questions about the study asked by the patient. Patients

must be informed that participation is entirely voluntary, that they may choose not to participate and that such a choice will have no impact on the quality of care provided to them, and they may withdraw from the study at any time without any effect on their care.

The patients will be given two copies of the consent form to review and sign; each form should also be signed by the physician and a witness. One copy of the consent form should be given to the patient for his/her records.

Once written consent has been obtained, the patient should be assigned the next available study identification number from the Study Identification Log (Appendix Q). On the Study Identification Log, next to the ID number, the patient's name will be recorded. The Study Identification Number will be recorded in the upper right corner of the first page of the consent form. The Study Identification Number will be used on all subsequent forms related to this study. Upon completion of the study the Study Identification Log will be destroyed.

Patients may choose to discontinue participation at any time. In addition, physicians may discontinue patient participation if, in their clinical judgment, continued participation by the patient will have an adverse impact on the patient's care or condition. Any patients that are discontinued for whatever reason will complete the discontinuation form.

Confidentiality

In order to collect information from participants on an ongoing basis, the names, addresses and telephone numbers of participating patients will be collected.

All individual identifying information and all clinical information collected that can be associated with an identifiable individual will be treated as confidential and stored in a secure place and separate from the patients' medical records. The study charts will be maintained in a locked area with limited access. As indicated above, the only time the patient's identity will be associated with the Study Identification Number is at the completion of giving informed consent. The Study Identification Log will be maintained in a locked cabined with access limited to the study team.

CHAPTER V

RESULTS AND DISCUSSION

The goal is to transform data into information, and information into insight.—C. Fiorina, (ThinkExist, 2007)

Humans Use Approval

The proposed study was reviewed by the Human Subjects Committee of the University of North Alabama (Institutional Review Board for the Protection of Human Subjects). The application was submitted on July 31, 2006, and based on the federal and university guidelines for the use of human subjects in research; the author requested the proposed research be considered for expedited review. The application was granted expedited review and approved on August 16, 2006, and a copy of the approval letter is included in Appendix R. The application is on file at the Northwest Alabama Cancer Center (The Custodian of Records is Mr. Jim Fowler, Office Manager) and the University of North Alabama, Office of Research, Planning and Institutional Effectiveness, Box 5121, Florence, AL 35632-0001, (256-765-4221).

The Questionnaires

Central to the study is the use of an array of questionnaires to measure aspects of religion and spirituality, various coping methods, and mental and physical well-being. Since the overall objective of the study was to improve spiritual growth and decrease spiritual decline through weekly intervention using spiritual narratives, it was necessary to examine many of these parameters during the times of intervention to ascertain if they were being influenced as well. This was especially true for those parameters previously reported to be related to the spiritual changes being measured, such as daily spiritual experiences, positive and negative affect, and depression (Cole et al. 2006). The majority of the data of this chapter deals with the information obtained from the weekly surveys during the intervention time. Since the interventions could have influenced the above mentioned parameters the survey results are necessary if a cause-and-effect relationship of the intervention is to be demonstrated.

Some of the survey instruments are public domain. For those instruments not of public domain the developers of the questionnaires were contacted and permission requested to use the surveys. In each instance the developer granted permission and requested feedback of the current study.

The patient population in question is one with high levels of emotional distress, and attempts were made to determine the practicality of completing the numerous survey questionnaires prior to initiation of the study. Patients on routine follow-up office visits, at least one year removed from the treatment of cancer, were asked to complete one of the questionnaires. Feedback was sought from the patient, and the time required to

complete the questionnaire was determined. A total of five patients at each office location were asked to complete each of the different questionnaires for a total of ten patients per survey. This occurred during the week of 28 August – 1 September 2006. There were no complaints about the nature of the questions or the time required to complete the survey. The results of the time required to complete the questionnaires are shown in Table 1.

Although there was considerable range in the time to completion, the average time of completion was close to that reported in the literature. However, one survey showed a major difference between the two offices, the BMMRS. The BMMRS questionnaires were reviewed and two of the five were responsible for the majority of the increased time, probably because the individuals completing these had taken the time to write explanations to their answers (more fully explaining doctrinal correctness) on the questionnaires. When these were eliminated the time to completion was more in line with the other office.

Thus, based upon this information patients were informed that the battery of questionnaires would take between 30 and 60 minutes to complete on each of seven consecutive weeks and again several weeks later. The patients are familiar with completing questionnaires about their previous week's health since we gather information to facilitate the flow of patients through the office every visit. This is usually done while waiting to see the physician and is does not take additional time from the patient and family.

Table 1

Time to Complete Questionnaire by Former Patients

Questionnaire	Time to complete (minutes) Average (standard deviation)		Reported in literature (minutes)
	Office one	Office two	
BMMRS*	7.2 (2.2)	14.6 (6.6)	Not reported
CES-D	4.4 (3.4)	2.8 (1.5)	5-10 (Sharp and Lipsky 2002)
DSES	4.0 (1.9)	3.0 (1.8)	2 (Underwood and Teresi 2002)
FACT-G	5.4 (3.4)	3.4 (0.9)	5-10 (Webster et al. 2003)
FACIT-Sp	4.2 (1.9)	2.4 (1.7)	< 5 (Webster et al. 2003)
PANAS-X	6.6 (3.3)	8.4 (4.7)	<10 (Watson and Clark 1994)
ROS	4.4 (0.5)	3.6 (1.5)	Not reported
STS	7.0 (2.8)	5.6 (3.0)	Not reported

*When those questionnaires that contained explanations were eliminated the average time to completion was 11 minutes (3.6).

Patient Accrual

Patients seen in the routine oncology practice of Northwest Alabama Cancer Center were eligible for participation in the study. The first ten patients in each office location who met eligibility criteria were approached by the author or a clinical nurse investigator for participation in the study. The majority agreed to participate in the study. Patient accrual occurred for the twelve week period (11 September 2006 thru 21 November 2006). Ten patients were enrolled in each arm. The dates of patient accrual and study status are shown in Table 2 and Table 3.

The intervention consisted of watching a video narrative about how a patient coped with cancer. The narratives written by the patients contained spiritual references and were referred to as the Spiritually Oriented Narratives (SON) or experimental group (Appendix S). A series of narratives were also produced in which each instance of spiritual/religious reference was removed and this series was referred to as the Factually Oriented Narratives (FON) or control group (Appendix T). The videos produced from the narratives are provided in Appendix U and Appendix V, respectively.

While the characteristics of the two groups would not be expected to be matched due to small sample size, they were close except for the average age as shown in Table 4.

The religious and other characteristics of the patients completing the study are shown in Table 5. The similarity of the religious activity and other volunteer and charitable activity is consistent with that reported previously (Clain and Zech, 1999). The high frequency of church attendance among those that attend church raises the

Table 2

Patient Accrual at Office One

Patient ID	Date enrolled	Study status
F-01	14 Sep 2006	**Completed study**
F-02	18 Sep 2006	**Completed study**
F-03	03 Oct 2006	Refused after first week on the study. Reason given: too much paper work
F-04	03 Oct 2006	**Completed study**
F-05	04 Oct 2006	Refused after second week on the study. Reason given: too much paper work
F-06	10 Oct 2006	**Completed study**
F-07	10 Oct 2006	Study interrupted due to unexpected surgery
F-08	30 Oct 2006	Refused after first week on the study. Reason given: too much paper work
F-09	30 Oct 2006	Patient noncompliant with study. Patient suffered from chronic depression and would refuse to participate some weeks
F-10	07 Nov 2006	Patient died after first week

Table 3

Patient Accrual at Office Two

Patient ID	Date enrolled	Study status
M-01	11Sep 2006	**Completed study**
M-02	12 Sep 2006	Refused to participate in study
M-03	12 Sep 2006	**Completed study**
M-04	18 Sep 2006	Patient refused due to becoming involved in church, therefore not interested in the study*
M-05	19 Sep 2006	**Completed study**
M-06	21 Sep 2006	After informed consent patient determined not to be literate
M-07	27 Sep 2006	**Completed study**
M-08	12 Oct 2006	Initiation of treatment delayed due to patient wanting to participate in drug protocol
M-09	14 Nov 2006	Patient noncompliant with study
M-10	21 Nov 2006	Refused after first week on the study. Reason given: too much paper work

*The patient had not been active in church prior to his diagnosis of cancer. From the time of his diagnosis until treatment was to start he became active in church and did not to participate in the study.

Table 4

Clinical Characteristics of Patients Completing Study

Variable	SON Group (Office one)	FON Group (Office two)
Age	83, 59, 66, 71	58, 58, 73, 50
Male	1	2
Female	3	2
Race; white, non -Hispanic	4	4
Type of cancer		
Lymphoma	1	
Breast	1	1
Ovarian		1
Lung	2	2
Performance status		
ECOG-0	1	2
ECOG-1	3	1
ECOG-2		1

Table 5

Religious and other Characteristics of Patients Completing Study

Variable	SON Group	FON Group
Religious affiliation		
Baptist		1
Church of Christ	1	
Methodist		2
Non-denominational	2	
None		1
Married Status		
Married	1	4
Widowed	3	
Tithes & Offerings ; $\geq$ 10%	3	2
Volunteer services $\geq$ 10%	3	1
Attend religious services		
$\geq$ weekly	4	1
< weekly		1
Never		2
Frequency of prayer		
$\geq$ daily	4	2
at least weekly		1
Never		1

Religious experiences	3	2
Self-description; religious		
Very	2	2
Moderately		1
Slightly	1	
Not at all	1	1
Self-description; spiritual		
Very	3	2
Moderately		
Slightly		1
Not at all	1	1

possibility of cancer precipitating this increased frequency. However, previous studies have provided little evidence that health factors increase religious attendance, and a diagnosis of cancer in the proceeding year actually results in less church attendance (Ferraro and Kelly-Moore, 2000). A higher frequency of personal prayer has been shown to result in improved psychological well-being (Maltby, Lewis, and Day, 1999).

The majority of the participants were retired or hourly employees. One in the FON group was a college instructor, and one in the SON group was an owner/operator of a construction company. Only one had completed college. Two participants had incomes above fifty thousand dollars annually. The median income is the area is about thirty-two thousand dollars annually.

There are numerous interesting differences between the two groups but attributing any significance to these differences, with the small sample size, would not be meaningful.

Religious Orientation Scale

The possible role of religious orientation in spiritual transformation was investigated. The Intrinsic-Extrinsic Religious Orientation System (ROS) of Allport and Ross (1967), which has become the basis of much of the psychological study of religion, was used. Although the ROS has not been without controversy, it is one of the dominant tools in the psychological study of religion in America, including minorities (Ghorpade, Lackritz, and Singh, 2006), and other cultures and societies (Brewczynski and MacDonald, 2006). The scale consists of twenty-one items rated on a four-point scale and includes twelve extrinsic and nine intrinsic items. Initially, based on the pattern of response, individuals were classified into one of two categories, either intrinsic or extrinsic. Intrinsically religious individuals are authentically committed to their faith, view religion as an end itself, internalized their religion, and follow it strictly. Extrinsically religious individuals are not genuinely committed to their faith, see religion as a means to another end, and pursue self as the end. The Allport-Ross subscales were used to classify individuals into two additional categories: indiscriminately pro-religious and indiscriminately anti-religious (Hood, 1978). A four component model eventually developed (Donahue, 1985), and the anti-religious category was changed to non-religious. The pro-religious type views religion in a noncritical manner and endorses all

items favorable to religion, scoring high in both extrinsic and intrinsic items. Those individuals scoring low on both intrinsic and extrinsic items are the non-religious. As reported in many studies, respondents were also assigned to the non-religious category if they self reported to be atheist, agnostic, or none. In the current situation the one individual scoring non-religious also self reported as not religious.

The results of the religious orientation of the patients completing the study are shown in Table 6.

Table 6

Religious Orientation System Scores

Religious Orientation	SON	FON
	Average (standard deviation)	Average (standard deviation)
Extrinsic scale	31.3 (10.2)	38.5 (13.3)
Intrinsic scale	38.5 (3.7)	30.8 (5.8)

The control group is composed of one non-religious individual, one pro-religious, and two functioning at the border of intrinsically religiously and pro-religious. The experimental group is composed of equal numbers functioning as intrinsically religious and pro-religious. Previously, it has been shown that the coping style of intrinsic and

pro-religious individuals was similar for stresses associated with cancer (Meyer, Altmaier, and Burns, 1992). The results are again consistent, with the exception of the non-religious individual, that there is no significant difference in the two groups of patients. Individuals intrinsically oriented are more psychologically adjusted, and extrinsic individuals are related to poorer mental health (Donahue, 1985). The response of older adults to laboratory stressors with blood pressure increase was found to be moderated by intrinsic religious orientation (Masters, Hill, Kircher, Benson, and Fallon, 2004). The relationship between religious orientation and depression was studied in five major denominational groups, and intrinsic individuals were least depressed (Genia and Shaw, 1991). Thus, there should not be anticipated differences in coping with cancer between the two groups.

Basic Multidimensional Religion/Spiritual Scale

Eleven variables have been identified as connected to religious behavior and spirituality that may influence health (Fetzer, 2004, p. 4) and are measured in the Brief Multidimensional Measures of Religiousness/Spirituality scale. Nine subscales lend themselves to comparative analyses in this particular study.

Although there have been some questions raised about the use of the BMMRS cross-culturally (Traphagan, 2005), all patients in the current study were associated with Judeo-Christian religions (Baptist x 1, Methodist x 2, Nondenominational x 2, Church of Christ x 2, and one had no affiliation). This denomination breakdown is not

characteristic of the church breakdown in our community and thus represents a selection bias to some degree secondary to the small sample size.

The BMMRS was taken at the initiation of the study and the results are shown in Table 7. Since the BMMRS was embedded in the 1997-1998 General Social Survey (GSS), the responses of the study patients were compared with the US population (Fetzer, 2004), because little information is available on elderly, white populations in rural areas such as northwest Alabama. Overall, the patients experienced more daily spiritual experiences (DSE) than the national average; the patients responded "every day" or "many times a day" at least 70 percent of the time compared to the GSS, which found that only 35 to 40 percent of the people responded in a similar fashion (Fetzer, 2004, p. 91).

The DSE domain "is intended to measure the individual's perception of the transcendent (God, the divine) in daily life and the perception of interaction with, or involvement of, the transcendent in life." (Fetzer, 2004, p. 11). This subscale consisted of six items with a six-point response format that ranged from 6 (never) to 1 (many times a day). The subscale was reverse scored so that individuals with more daily spiritual experiences scored higher. The same pattern will be followed in subsequent domains.

Thus, the total daily spiritual experience score could range from six (never) to thirty-six (many times a day). The control group showed more variability due to one individual who described himself as being non- religious and non-spiritual and without any daily spiritual experiences. When that individual is removed, the DSE for the control group becomes 28.7 (SD = 5.6), which is very similar to the experimental group. In a

Table 7

Brief Multidimensional Measure of Religiousness/Spirituality Scores

Variable	SON	FON
Daily spiritual experiences	29.4 (2.8)	23 (12.6)
Meaning	6 (1.4)	6 (0.8)
Values/Beliefs	7.5 (0.6)	6.3 (1.7)
Forgiveness	11.5 (0.6)	9.5 (3.1)
Private religious practices	27 (5)	20 (10.2)
Religious/Spiritual coping	22 (3.2)	20 (8.4)
Religious support	11.8 (2.9)	7.8 (4.3)
Commitment	3.5 (0.6)	3.3 (0.9)
Organizational religiousness	10 (2)	3.3 (1.5)

recent study among rural elderly whites the similar results were reported with a mean DSE score of 24.28 (SD = 4.87) (Yoon and Lee, 2004).

The domain of ‘meaning’ is essentially a human endeavor (Fetzer, 2004, p. 19) and is void of religious or spiritual perspective. To this end it should be noted that the subscale scores are identical between the groups even when the non-religion individual is included in calculations. Similar results were seen with the ‘Meaning and Purpose’

subscale of the FACIT-Sp scale which is designed to be independent of religion (see figure 32).

The values and beliefs subscale measures value and beliefs systems associated with religion (Fetzer, 2004, p. 25-33). Individuals often base their response to illness on their values and beliefs. This subscale consists of two four-point items with responses ranging from 1 (strongly agree) to 4 (strongly disagree). The values/beliefs domain of elderly whites in West Virginia and North Carolina was similar at 6.59 (SD = 1.31) (Yoon and Lee, 2004). As with the GSS sample, 90 percent agree or strongly agree that "God watches over me," and this was true with the patients as well. However, in reference to a "deep sense of responsibility for reducing pain and suffering in the world," 60 percent of the respondents of the GSS indicated agree or strongly agree, but greater than 90 percent of the patients so indicated.

Forgiveness, so central to the Judeo-Christian tradition, contains three items: forgiveness of self, forgiveness of others, and forgiveness by God (Fetzer, 2004, p. 35). The scale for forgiveness ranged from 3 (always) to 12 (never). Interestingly, the two individuals experiencing the lowest scores on forgiveness are the one who also experienced the lowest daily spiritual experiences scores. Again, similar values for elderly whites in rural America was 9.67 (SD = 1.31) (Yoon and Lee, 2004). In the GSS survey about 45 percent of the respondents indicated "always/almost always" with forgiving self and forgiving others and 75 percent knowing "God has forgiven me." In the patient population the corresponding percentages were 45, 50 and 85 percent, respectively.

The private religious practices domain is designed as “a conceptual domain or dimension of religious involvement often characterized by terms such as nonorganizational, informal, and non-institutional religiosity.” (Fetzer, 2004, p. 39). The subscale consists of four items with eight possibilities, and one item with five possibilities. The possible answers ranged from never to more than once daily and resulted in a total score range from five to thirty-seven, with the latter representing the maximum value for private religious practices. Half of the patients have private prayer more than once daily compared to about 25 percent in the GSS group, and about 25 percent have daily Bible or religious literature reading compared to 8.1 percent in the GSS sample (Fetzer, 2004).

Religious and spiritual coping scores are designed to measure skills in coping with stressful problems of life (Fetzer, 2004, p. 43). The subscale consists of seven items and a 4-point response possibility. Reverse scoring was used for questions 22, 23, and 24 reflective of religious struggle in coping. The patients tended to view life as part of a larger force more than the GSS sample (62 percent compared to 40 percent “quite a bit/a great deal”) and to view their working with God (62 percent compared with 44 percent). The patient population looked to God for strength about 75 percent of the time compared to 63 percent of the time in the GSS sample. Both were similar in not viewing their illness as punishment from God or as being abandoned at least 75 percent of the time.

Religious support is a subscale designed to “measure select aspects of the social relationships between study participants and others in their shared place of worship.” (Fetzer, 2004, p. 57) The subscale has four items with four possible responses with a total score from four to sixteen (most relationship). Two items deal with help to the

respondent from the religious organization, and two items deal with demands made on the respondent by the religious organization. A score of eight could indicate a great deal of support from the organization and little demands or just the opposite. However, in each instance the respondents did not view the organization as making demands more than "once in a while". The patients saw their religious support as favorable about ten percentage points higher than the GSS.

In response to the question "Did you ever have a religious or spiritual experience that changed your life?" the patient population responded yes 70 percent of the time, compared to about 40 percent for the GSS survey. However, part of this is somewhat misleading since some Protestant groups shy away from the term "experience" and emphasize "decision making."

About 90 percent of the study patients "agree/strongly agree" with the statement "I try hard to carry my religious beliefs over into all my other dealings in life." Only about 28 percent of the population answered accordingly in the GSS. Interestingly, in the GSS 44.7 percent disagreed with this statement, and 27.7 percent strongly disagreed. This statement has far-reaching implications in a society in which a seminary Doctor of Ministry program is intentionally training graduates with an emphasis in "Christianity in the Workplace."

Attendance at religious services was stronger in the patient group than in the GSS group. About 50 percent of the patients attend services at least weekly compared to about 25 percent in the GSS. About 12 percent of the study sample never attends, compared to twenty percent of the GSS sample. The population represented 75 percent Protestant,

12.5 percent Catholic, and 12.5 percent none, compared with 54.2 percent, 25.7 percent and 13.8 percent respectively in the GSS.

While there are differences between the sample population and those of the GSS probably reflective of the geographical region, the sample does seem to be representative of a larger population of rural elderly white, African American, and Native Americans living in West Virginia and North Carolina (Yoon and Lee, 2004). Overall, there is probably no difference in the control and the experimental groups of the population. While there is individual variation, there was no difference in the groups. Any differences observed after a period of intervention would probably not be due to differences in baseline religiousness and or spirituality.

Interestingly, the majority of the differences disappear if values due to the nonreligious individual are removed. When the sample size is small, the inclusion of outlying results from someone who has no religious experiences, when most everyone else has some, does produce noticeable changes in data generated. In our sample one nonreligious person out of four in the control group is 25, whereas in the data from Cole's work (Cole et al. 2006) similar data is diluted when she had only two percent of the sample size with no religious affiliation.

Although the sample size of those who completed the study is too small to make significant comparisons, when the data from all ten eligible patients in each group is included, the averages are more similar. Since the BMMRS was taken on the first visit and the majority of eligible patients completed this paperwork the data was included in the discussion of the values with the GSS data above.

Daily Spiritual Experiences Scale

The daily spiritual experiences (DSE) scale is an expanded scale of the concept found in the BMMRS. The questionnaire consists of sixteen items; all but the last are scored such that a lower score indicates more frequent DSE (many times a day =1, and never or almost never = 6). One question contains only four options. (Underwood and Teresi, 2002). The weekly daily spiritual experiences scales are shown in figure 1 for each group.

There is considerable variation between the groups for this scale. This is primarily due to the small sample size being heterogeneous (one fourth of the control group having no spiritual experiences). Since the DSE scale is intended to measure an individual's experience with God on a daily basis, it goes without saying, that if one has no experience with God, that the score will be very high. As the sample size increases, the influence of the "no spiritual experiences" individual will be diluted since few such individuals would be expected.

The DSE scale was included in this study to determine if any correlation existed between spiritual growth and/or spiritual decline as measured on the spiritual transformation scale and the DSE score. In the studies by Cole (Cole et al. 2006), a positive correlation between scores on the DSE and the STS was reported. Since the study described herein was one of spiritual intervention, it was of interest to determine if the weekly intervention resulted in any change in the daily spiritual experiences. The data indicates that the interventions, either spiritual or factual, had no significant influence on the weekly DSE of the study participants.

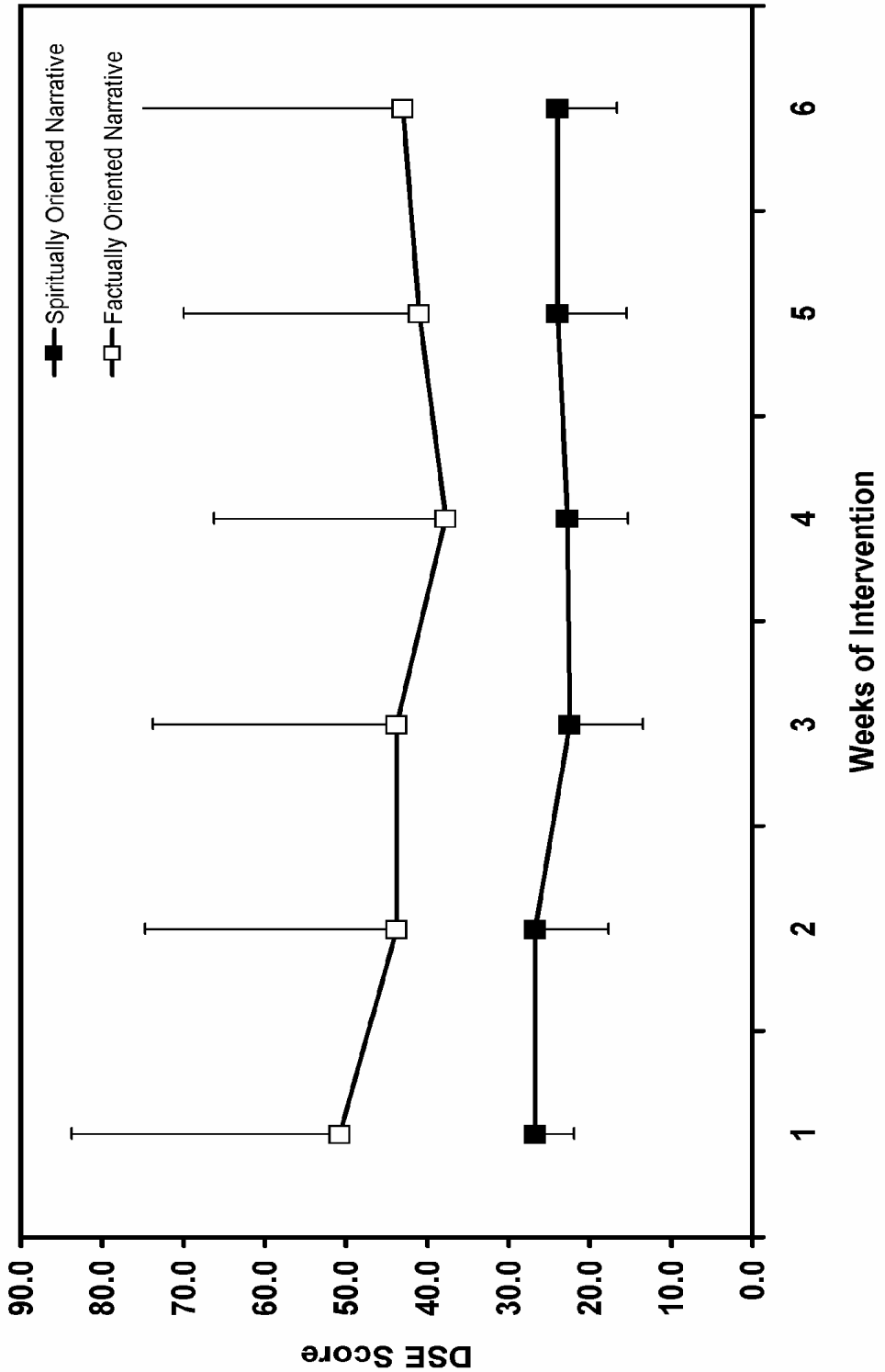


Figure 1. Weekly total score on daily spiritual experiences (DSE). A lower number indicates more spiritual experiences.

The DSE scale includes measurements of several items, and these are shown in the following figures. In addition, the information from this study will be compared with that obtained from the national survey of the United States population (GSS 2004).

Connection with the divine or transcendent is important in all religion and spirituality and is addressed in the DSE in two questions (Underwood, 2006): "I feel God's presence, and I feel a connection to all of life." The 'connection' subscale of the DSE is shown in figure 2.

In the 2004 GSS, 21.4 percent of the respondents reported "I feel a connection to all of life" at least daily, whereas 25 percent of the FON group and 75 percent of the SON group reported the same. In the GSS group 13 percent reported a connection "never/almost never," and in the study sample no one choose this option. With respect to the question framed in more theistic terms: "I feel God's presence," 25.6 percent of the US population experience this daily (GSS 2004). In the FON group 50 percent experience God's presence daily, and in the SON group it was 75 percent. In the GSS 22.4 percent never/almost never experience God's presence and one individual in the FON group made this choice, and no one in the SON group.

Another item of the DSE scale is that of 'joy and transcendent sense of self' detected from the question "During worship, or at other times when connecting with God, I feel joy which lifts me out of my daily concerns." The results of the patient population during the time of intervention are shown in figure 3.

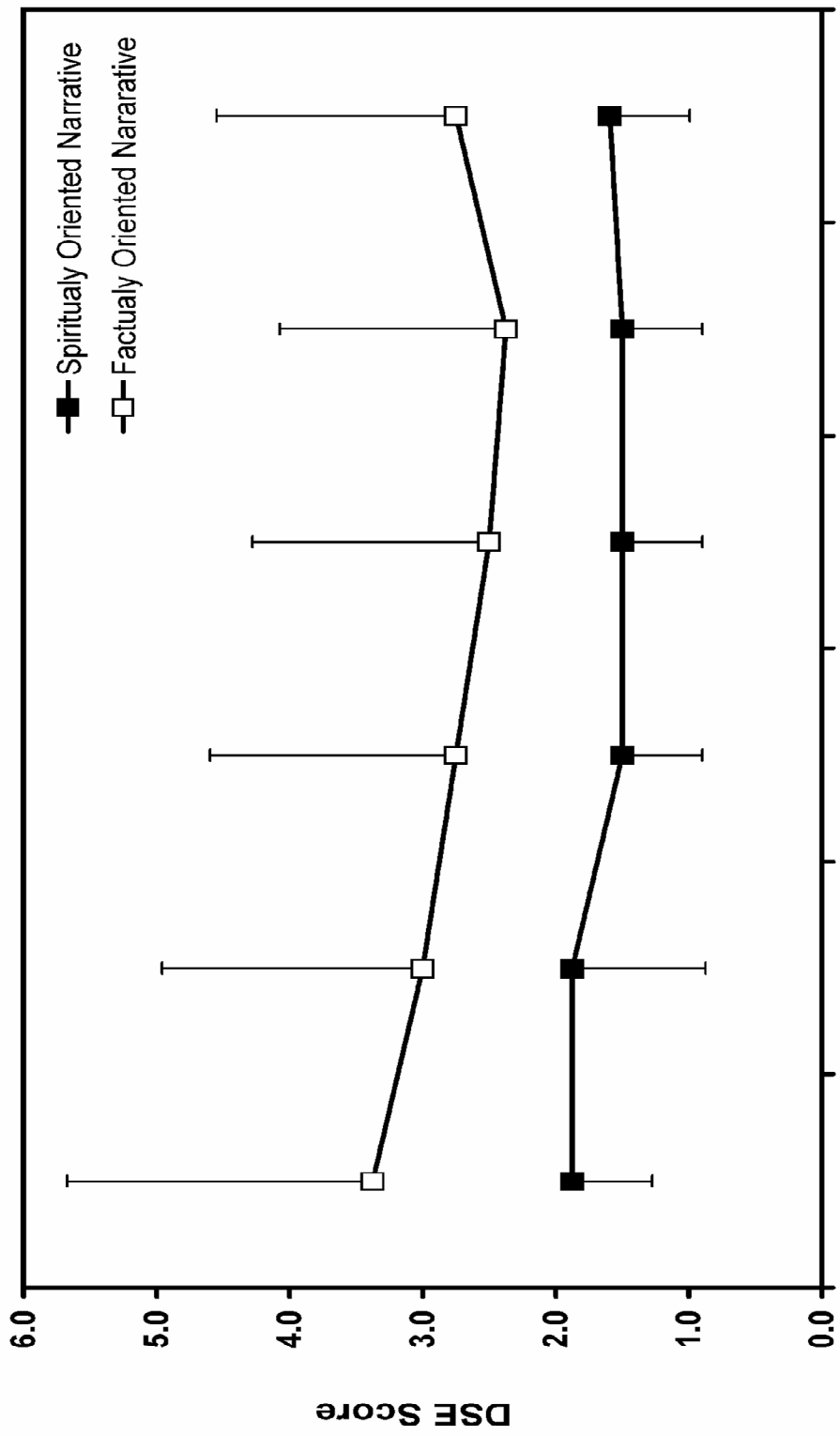


Figure 2. Weekly score for connection with the divine or transcendent.

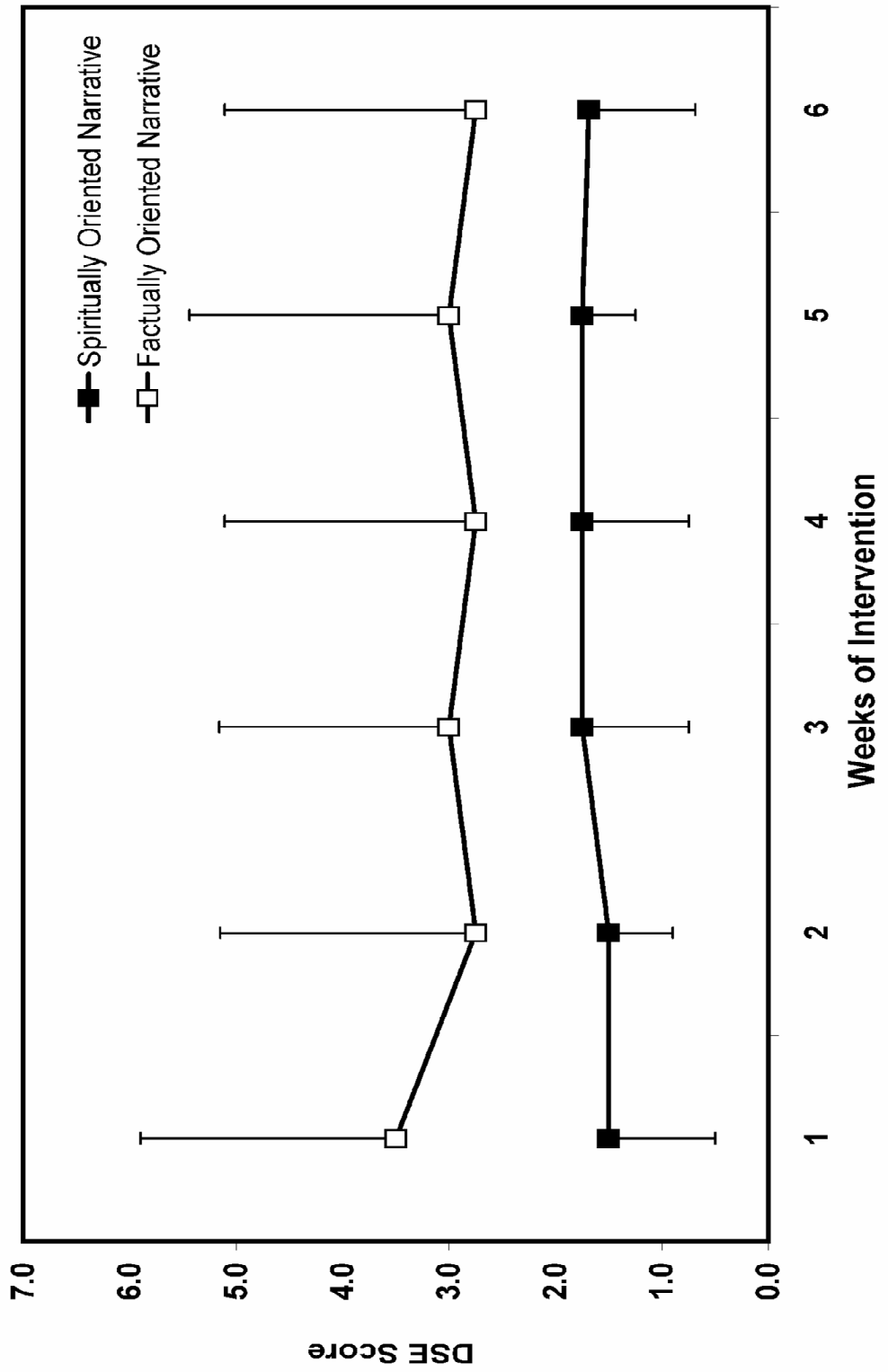


Figure 3. Weekly score for joy/transcendence sense of self.

In the 2004 GSS, 29.6 percent of the US population experience 'joy/transcendence sense of self' at least daily. This was somewhat higher in both groups in the study population with the FON experiencing this 50 percent of the time on at least a daily basis and the SON group without exception at least daily.

The 'strength and comfort' score are daily spiritual experiences derived from a combination of questions 4 and 5: "I feel strength in my religion or spirituality. And I feel comfort in my religion or spirituality", and are shown in figure 4.

Likewise, the FON group experienced this at least daily 50 percent of the time, and the SON group 100 percent of the time. The 2004 survey found about 20 percent of the population experienced strength or comfort at least daily.

The DSE also measures 'peace' based on question 6. "I feel deep inner peace or harmony." The results are shown in figure 5.

Whereas 50% of the FON group and 75% of the SON group experience deep inner peace on at least a daily basis, only 17.1 percent of the US population reported doing so in 2004 (GSS). In contrast, no one in the study group reported never/almost never experiencing deep inner peace, 14.7 percent of those in the GSS reported never/almost never experiencing this.

The DSE scale addresses 'divine help' in the form of question 7: "I ask God's help in the midst of daily activities." (Underwood, 2006, p. 9) referenced Pargament (1990) as suggesting that "the collaborative coping style, where one works together with God, is most productive of psychological well-being." The results are shown in figure 6.

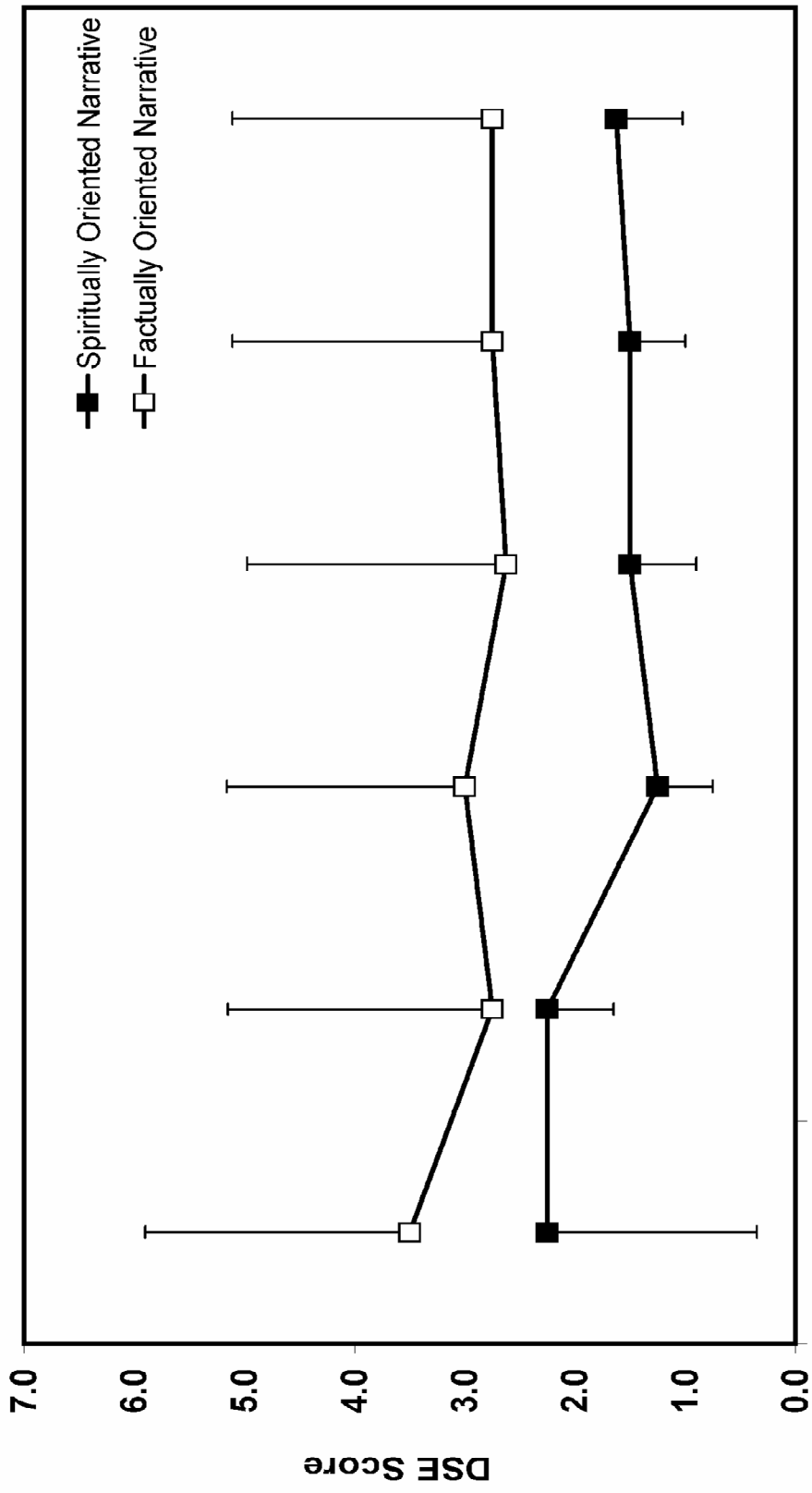


Figure 4. Weekly score for strength/comfort.

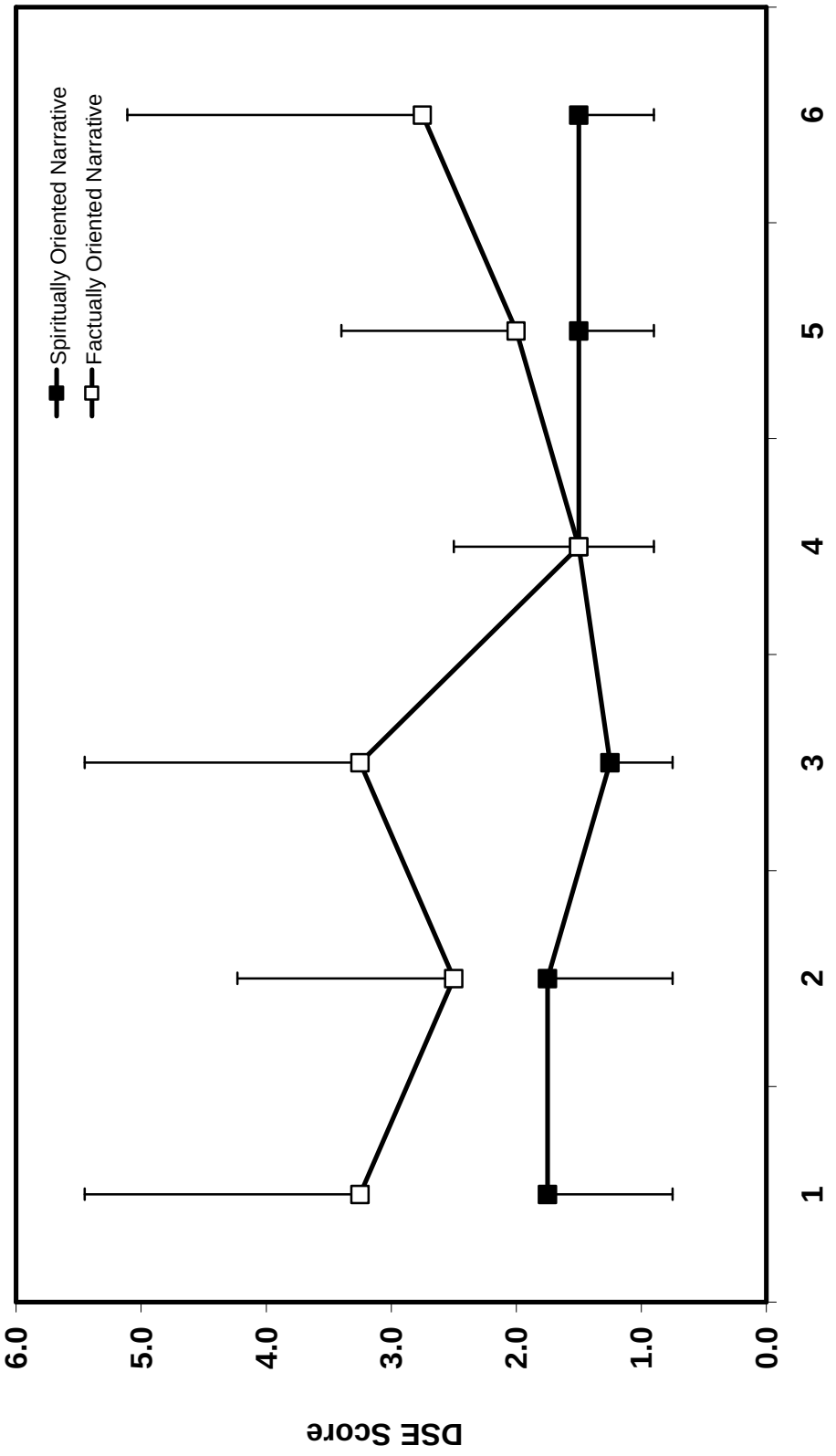


Figure 5. Weekly score for peace.

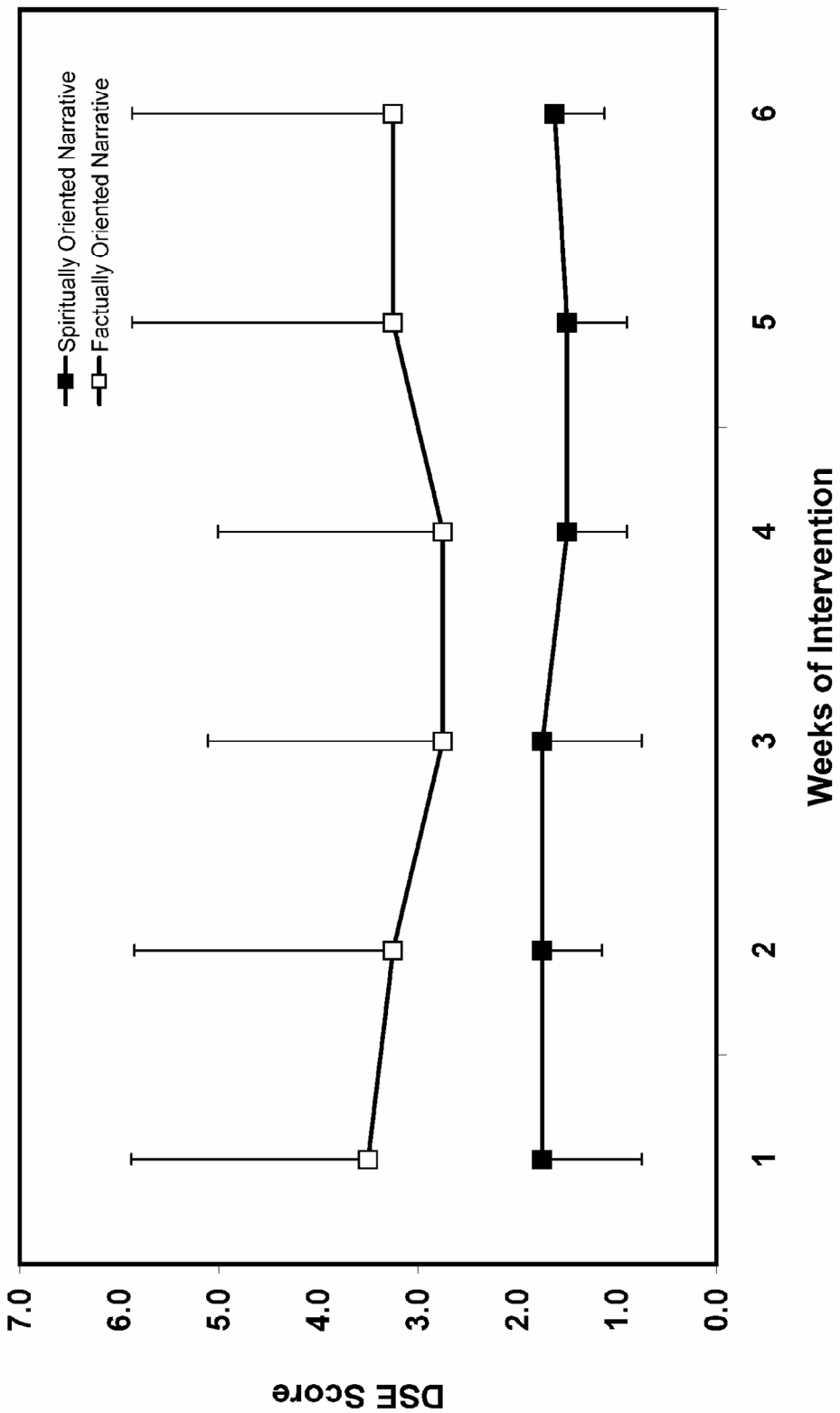


Figure 6. Weekly score for divine help.

About 25 percent of the US population in 2004 asked for divine help on at least a daily basis. In the SON group this was 100 percent and half that in the FON group in the sample of patients. While almost one fourth of people in the US never/almost never ask for divine help only one person in the study sample so indicated, and that was the one person in the FON group who reported no spiritual experience.

The same individual never experienced 'divine guidance' as well. This item is based on question 9 of the DSE scale: "I feel guided by God in the midst of daily activities." The patient experiences are shown in figure 7.

One fourth of the FON group and three times that many of the SON group experience this on at least a daily basis, compared with 29.1 percent of US population in 2004.

Perceptions of 'divine love' was another item measured on the DSE scale. The score was obtained from a combination of two questions: "I feel God's love for me, directly, and I feel God's love for me, through others." The results are shown in figure 8.

About one fourth of the US population has at least a daily perception of divine love. About 20 percent never/almost never feel love directly from God, and 15 percent never/almost never from others. Fifty percent of the FON group had at least a daily perception of such, and everyone in the SON group experienced divine love at least daily. The same individual in the FON group never/almost never perceived divine love.

'Awe' is an item included in the DSE that goes across religious and non-religious boundaries (Underwood, 2006). Perhaps this is why no one in the study groups marked

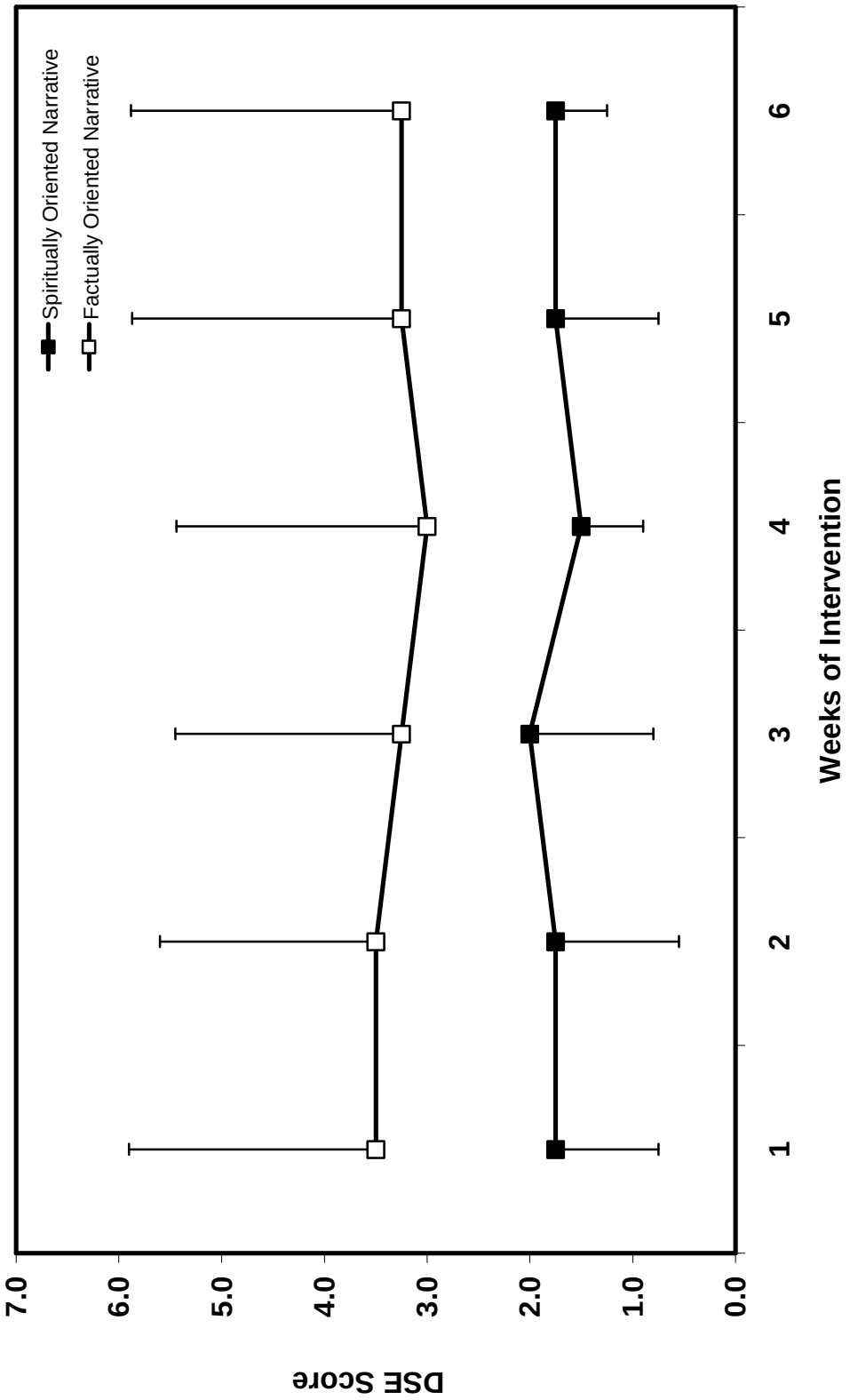


Figure 7. Weekly divine guidance score.

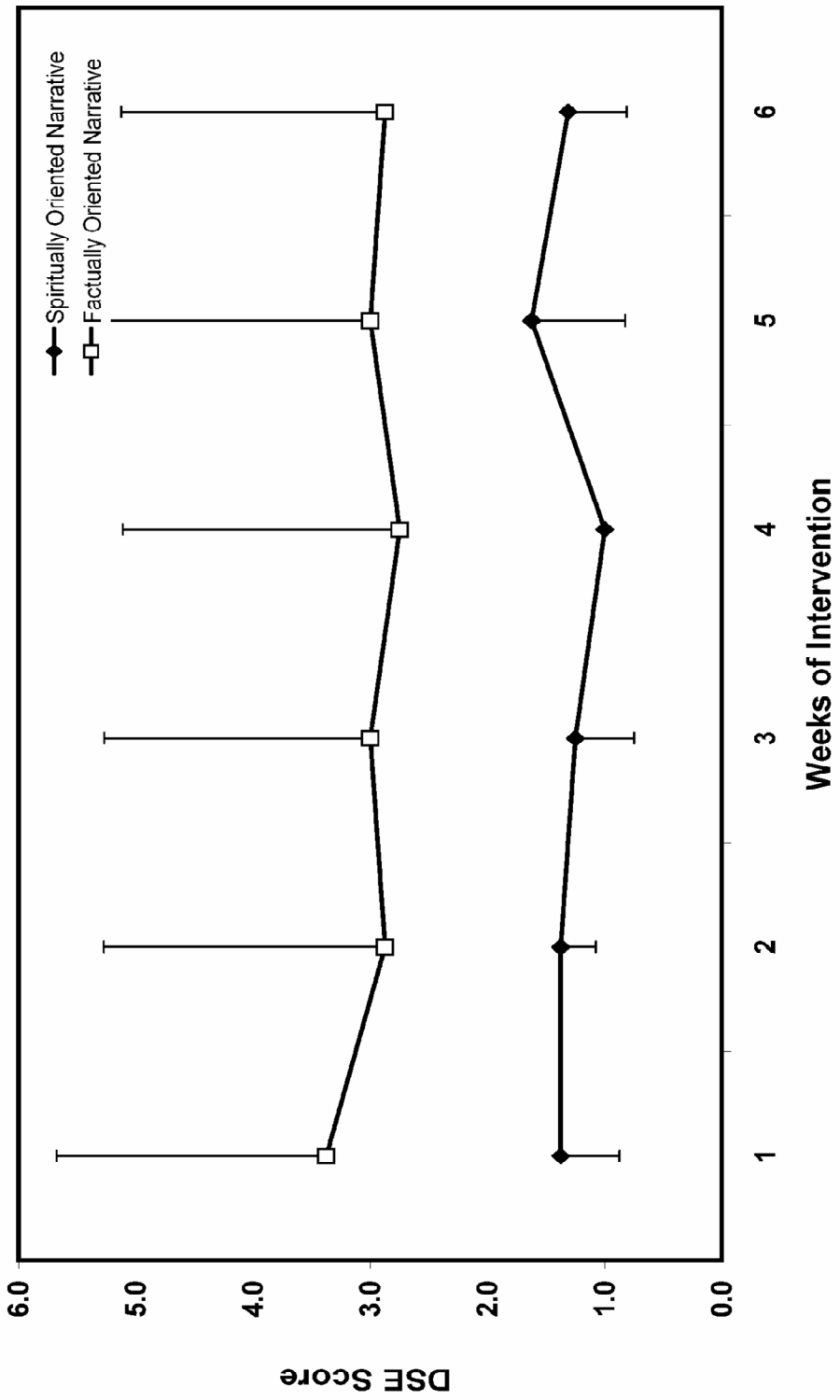


Figure 8. Weekly score for perceptions of divine love.

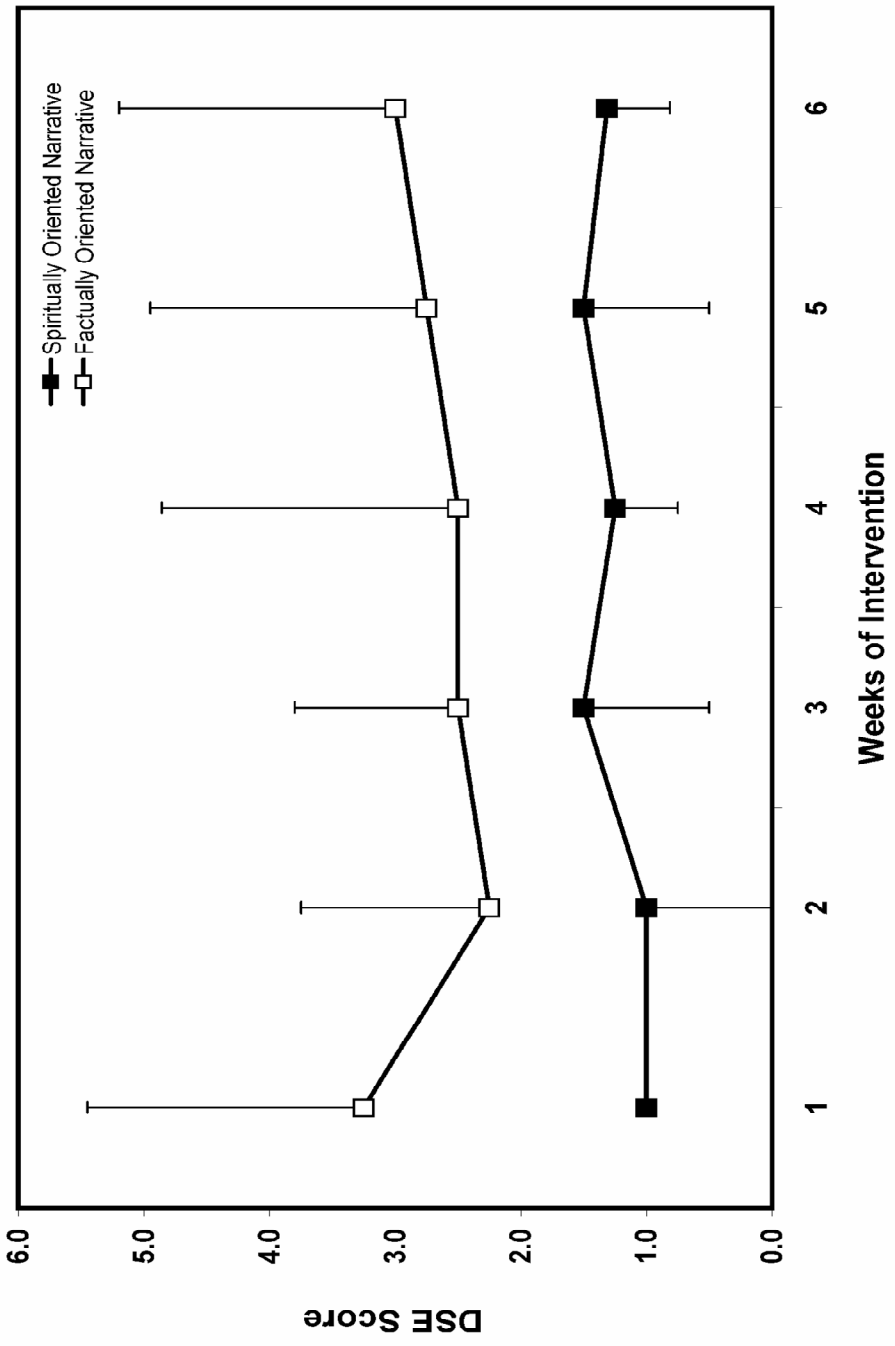


Figure 9. Weekly score for awe.

never/almost never in response to this question: “I am spiritually touched by the beauty of creation,” especially with the love for the outdoors so common in the area where the study occurred. About twenty percent of the US population reported never/almost experiencing this. The results during the six weeks of intervention are shown in figure 9.

In the FON group 50 percent experienced awe on at least a daily basis and 75 percent of the SON did so, compared with only 13.7 percent of the US population in 2004.

The most striking difference in our small sample size is shown in the figure 10 dealing with ‘thankfulness and appreciation.’ This item of the DSE is based on question 12: “I feel thankful for my blessings.”

All individuals in the SON group experienced this on at least a daily basis, and 50 percent of those in the FON group did. This is compared to only 4.1 percent of the US population in 2004. No one in either study group experienced this ‘never/almost never,’ and in the GSS a significant portion of the population marked this choice, namely 30.9 percent. In the US population survey thankfulness and appreciation are two of the least frequently reported items. The mean score in the 2004 GSS was 4.88 (SD 1.11) (Underwood, 2006).

The next two questions on the DSE assess ‘compassionate love’: “I feel a selfless caring for others, and I accept others even when they do things I think are wrong.” No one in the study groups marked never/almost never for the former question, but one did for the later question. In the 2004 GSS that choice was indicated 14.1 and 10.7 percent of the time, respectively. The results of six weeks of intervention are shown in figure 11.

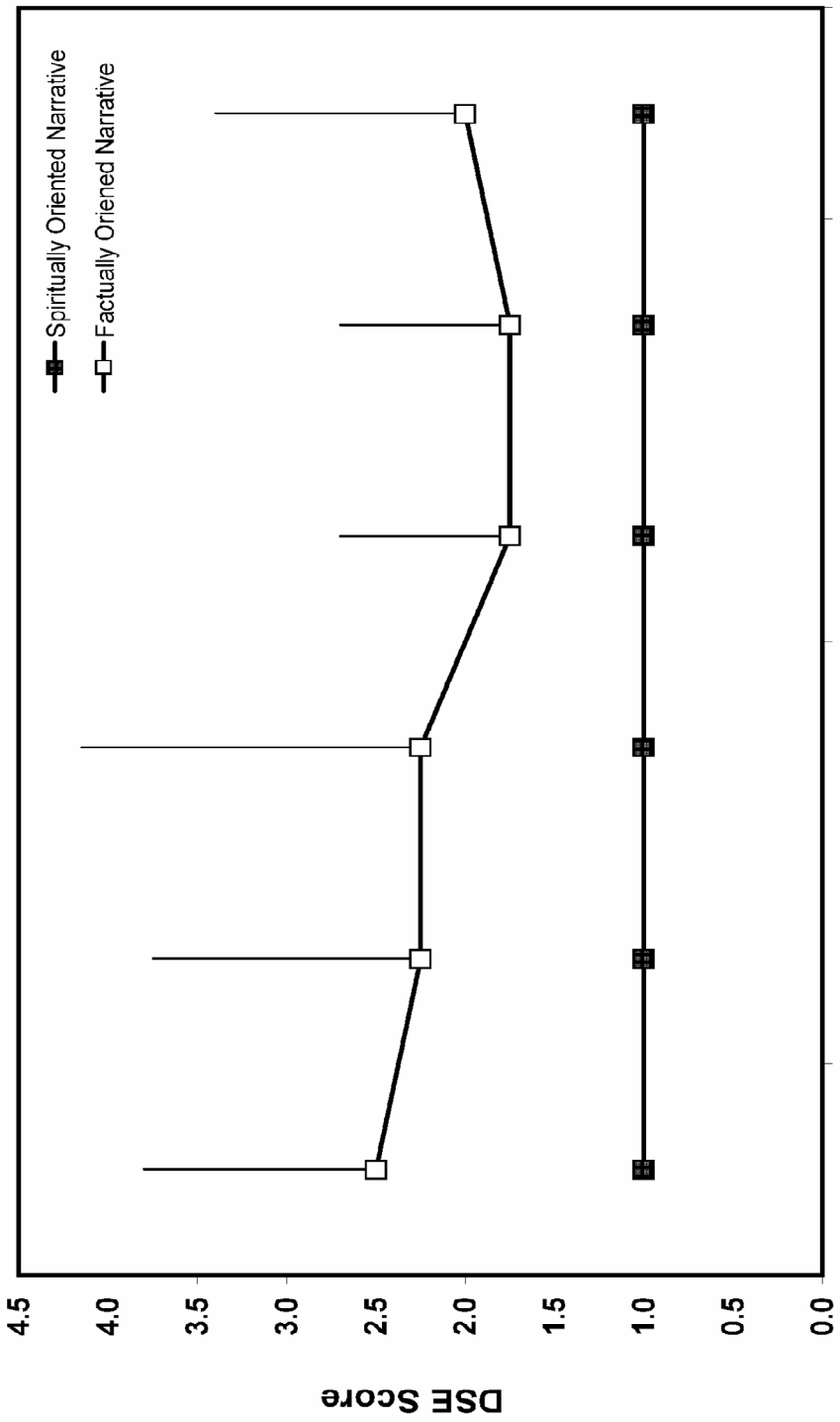


Figure 10 . Weekly score for thankfulness and appreciation.

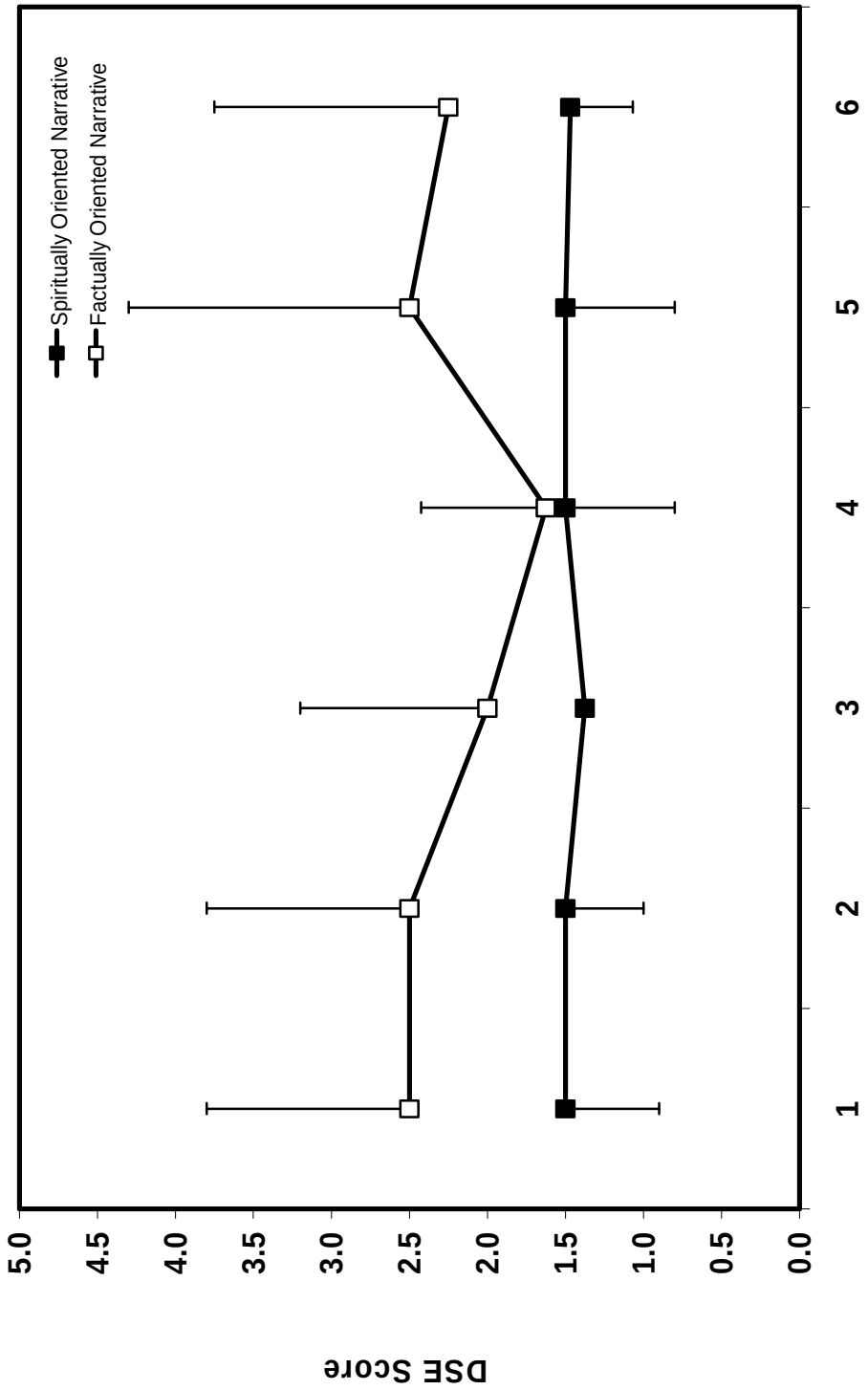


Figure 11. Weekly score for compassionate love.

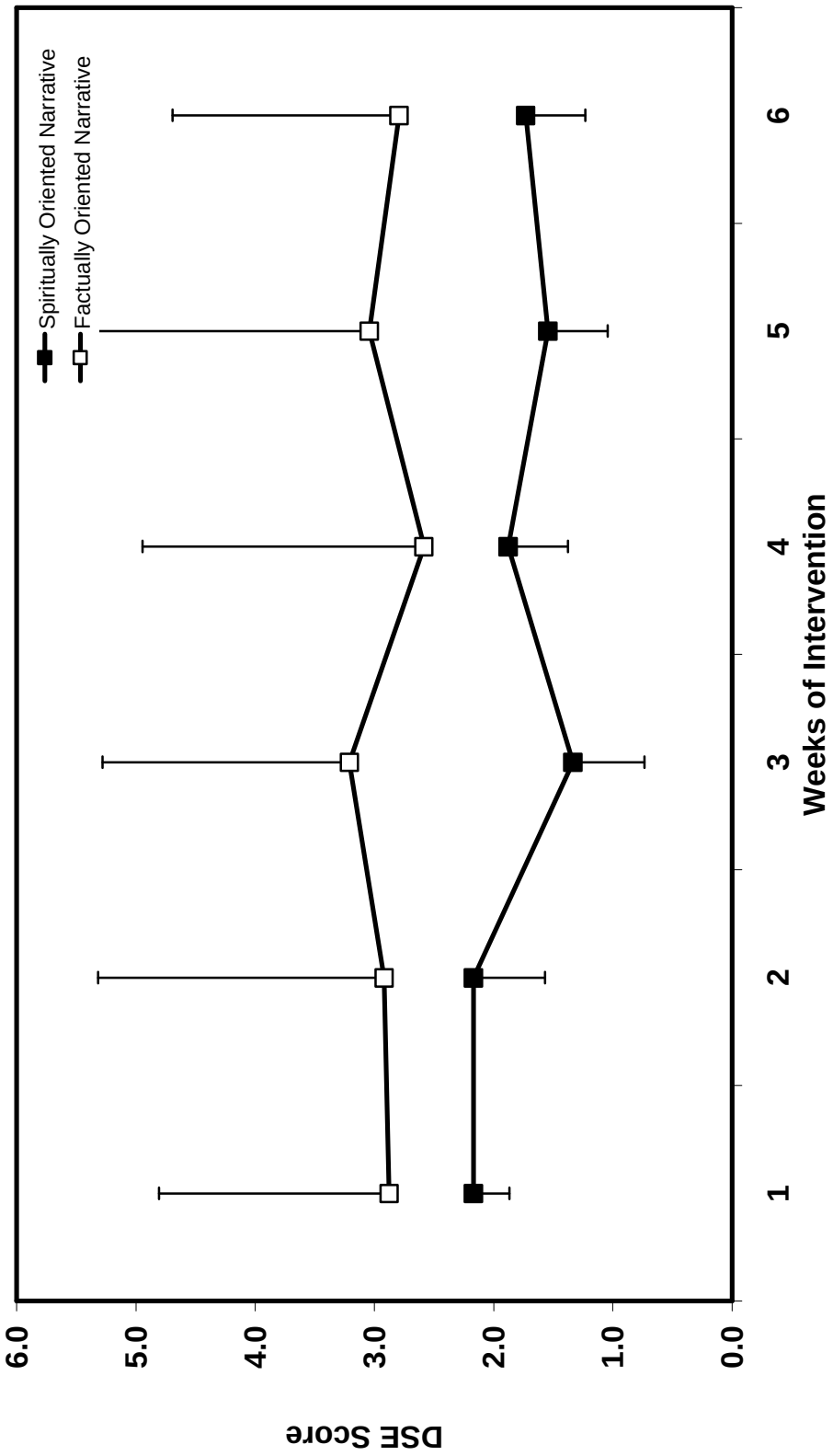


Figure 12. Weekly score on union and closeness.

In the FON group 25 percent experienced selfless caring at least daily, and 50 percent experienced acceptance of others at least daily, while 100 percent of the SON experienced both of these at least daily.

The final pair of items of the DSE involves a desire for 'closeness to the divine.' It is a composite of two questions: "I desire to be closer to God or in union with the divine and In general, how close do you feel to God?" In the study population the SON ranked 100 percent at least daily on both these questions and the FON sample 50 percent. This compared to the US population in 2004 of 20.5 percent and 47.2 percent, respectively. The DSE score related to union and closeness to the divine is shown in figure 12.

In each instance there was little change over the six week period of intervention regarding each of these aspects of spiritual experiences, and there was little difference noted between the two that was not attributable to the one individual reporting no spiritual experiences.

Depression Scale

The majority of newly diagnosed cancer patients just beginning treatment with chemotherapy did not exhibit depression. The fluctuation of depression is similar with both groups and may reflect the time from onset of chemotherapy treatment. The weekly depression score shown in Figure 13 reveals no differences between the two groups of patients.

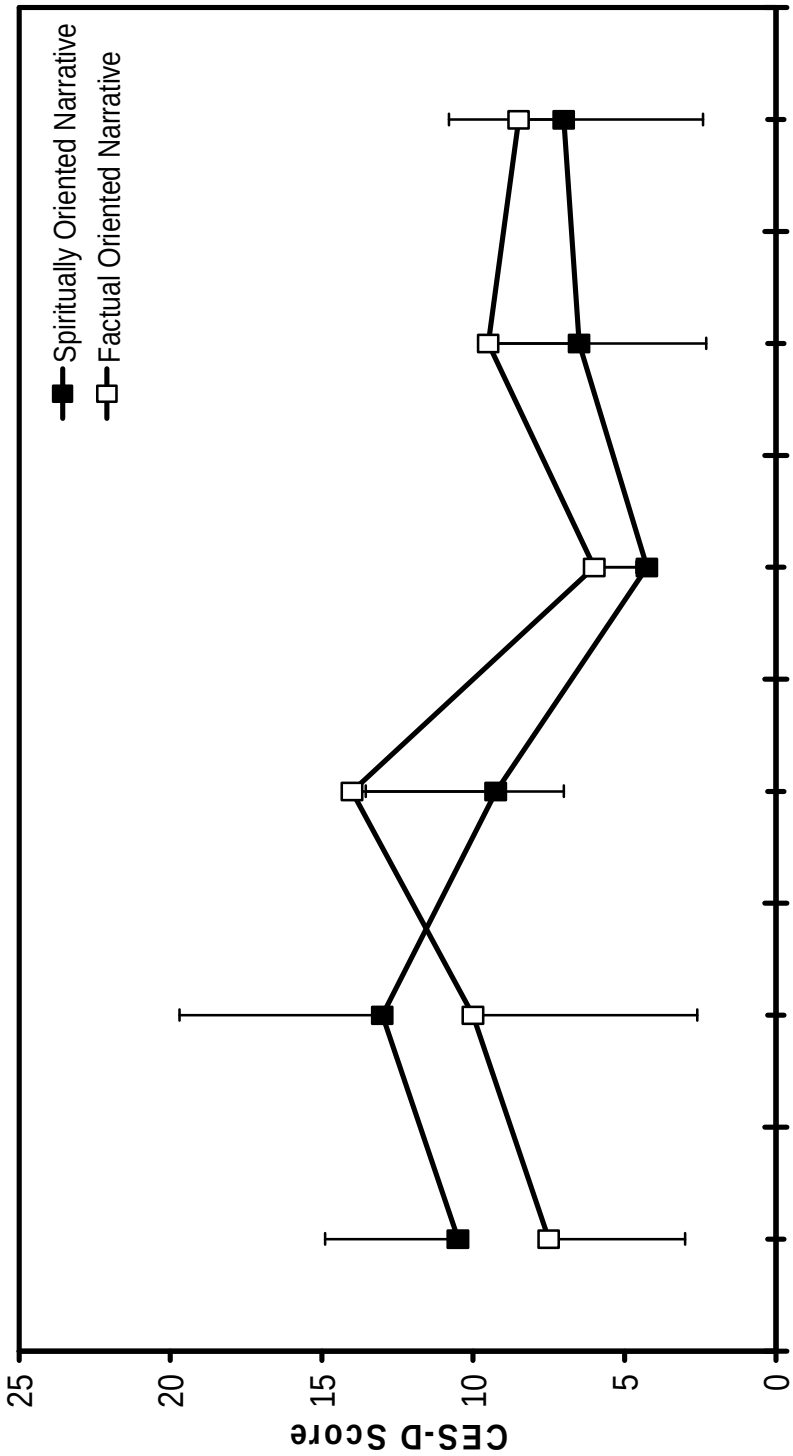


Figure 13. Weekly depression scores as measured by the Center for Epidemiologic Studies Depression Scale (CES-D).

About 25% of the patients did exhibit mild to moderate depression during the first one to three weeks. However, by the second treatment of chemotherapy this had usually resolved without medication (Figure 14).

The overall emotional stability of the patients in both groups of patients was observed in the other measurements used as well. For example, see the positive and negative affect scale of the PANAS-X scale and the emotional well being scale of the FACT-G scale to follow.

Positive and Negative Affect Scale

Psychological adjustment was measured by the Positive and Negative Affect Schedule – Expanded Form (PANAS-X) (Watson and Clark, 1994/1999). Patients were asked to rate their feeling or behavior during the past week in response to individual words or phrases that represent different feelings and emotions from 1 (very slightly or not at all) to 5 (extremely). The PANAS-X assesses both positive and negative aspects of mood. While the PANAS-X was developed and validated on college students it has been used and validated in studies of mood in general (Watson and Clark, 1994/1999) and in cancer in particular (Manne and Schnoll 2001; Park and Blank 2006).

The weekly positive scores of the PANAS-X scale are shown in figure 15. There was essentially no difference between the two groups of patients either at baseline or during the six weeks of intervention. The negative affect scores for the same groups revealed similar findings as shown in figure 16.

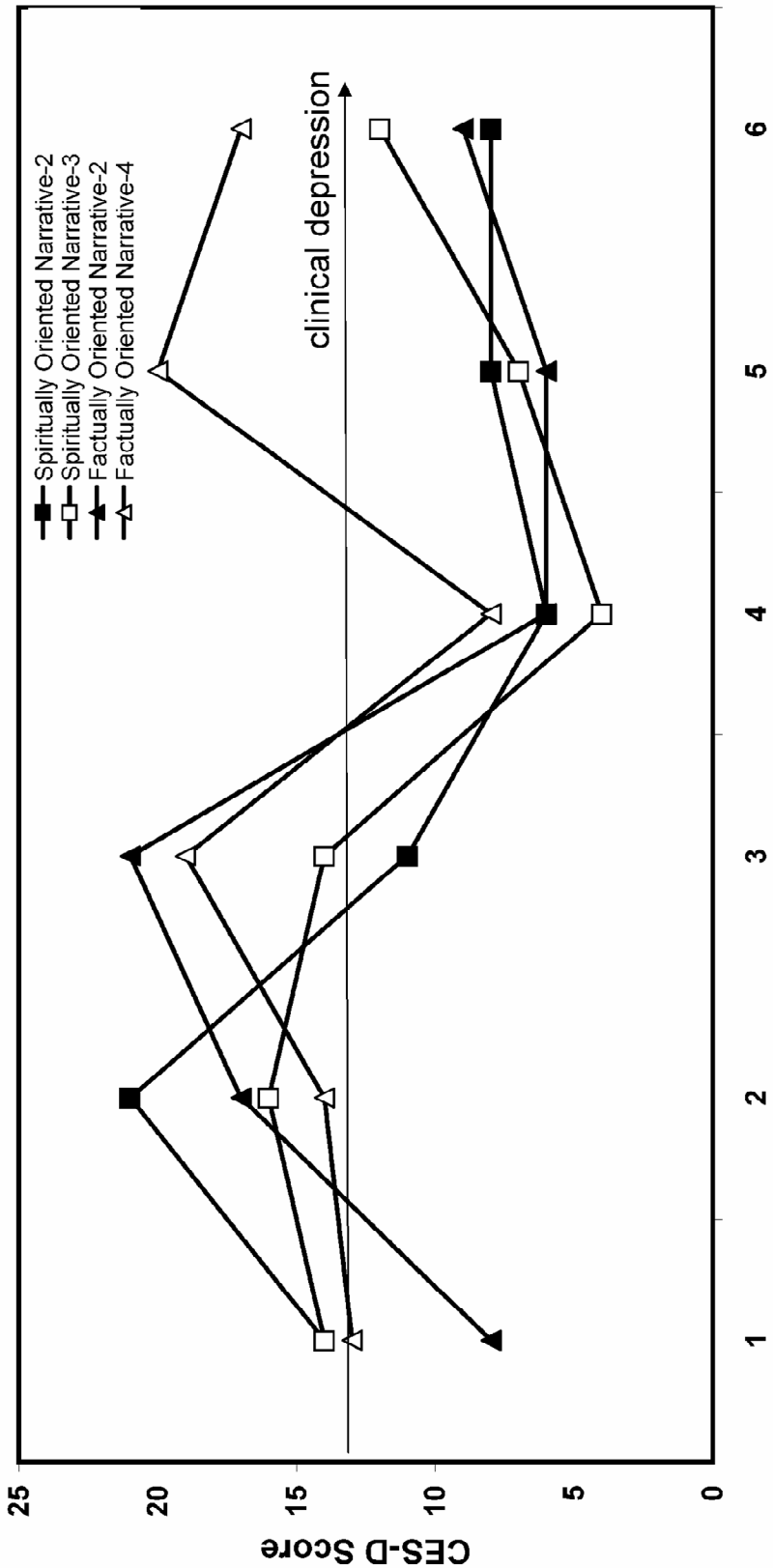


Figure 14. Weekly depression scores as measured by the Center for Epidemiolgical Studies Depression Scale (CES-D) of patients scoring clinical depression at any time during the period of intervention.

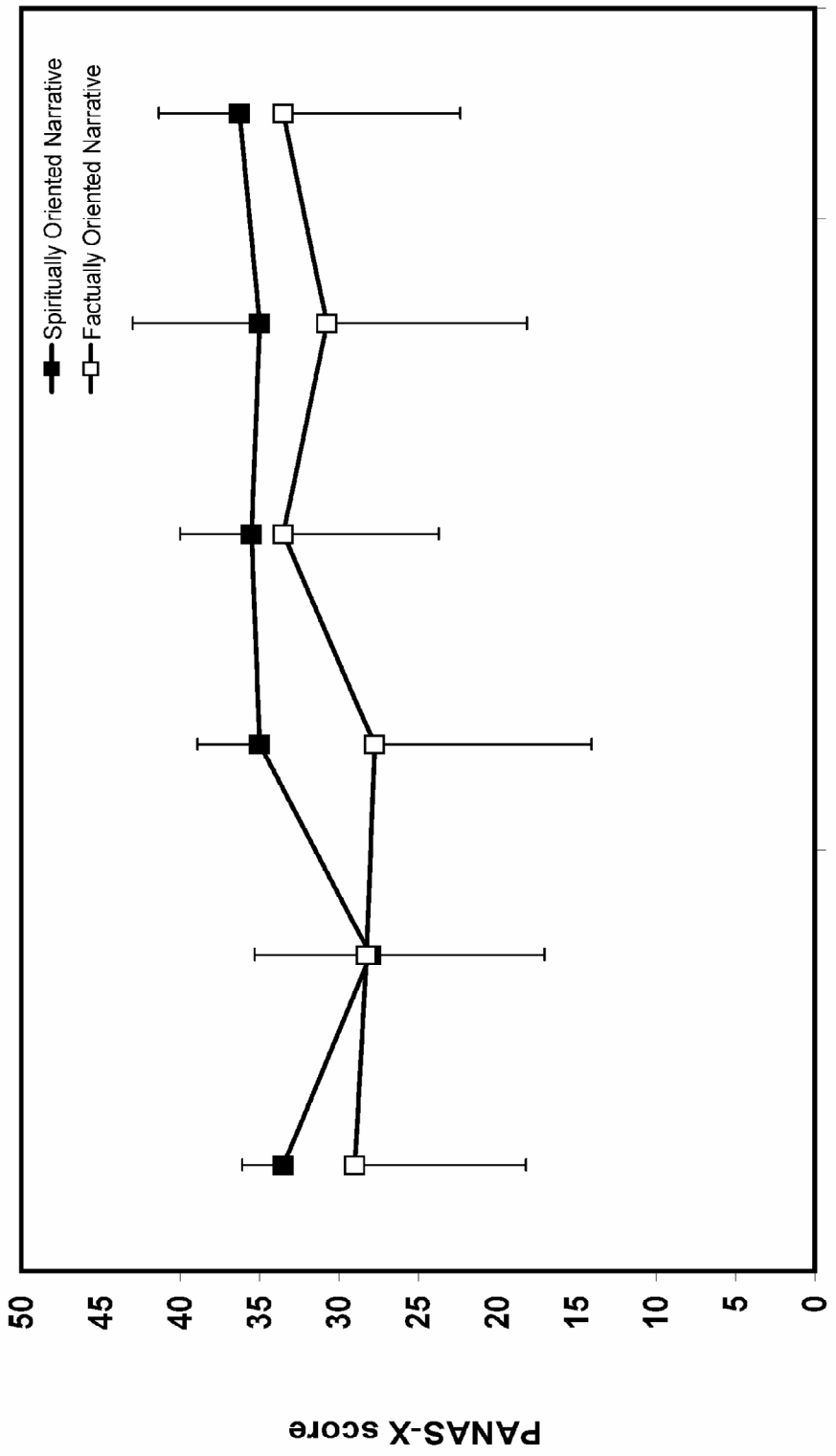


Figure 15. Weekly positive affect scores measured by PANAS-X.

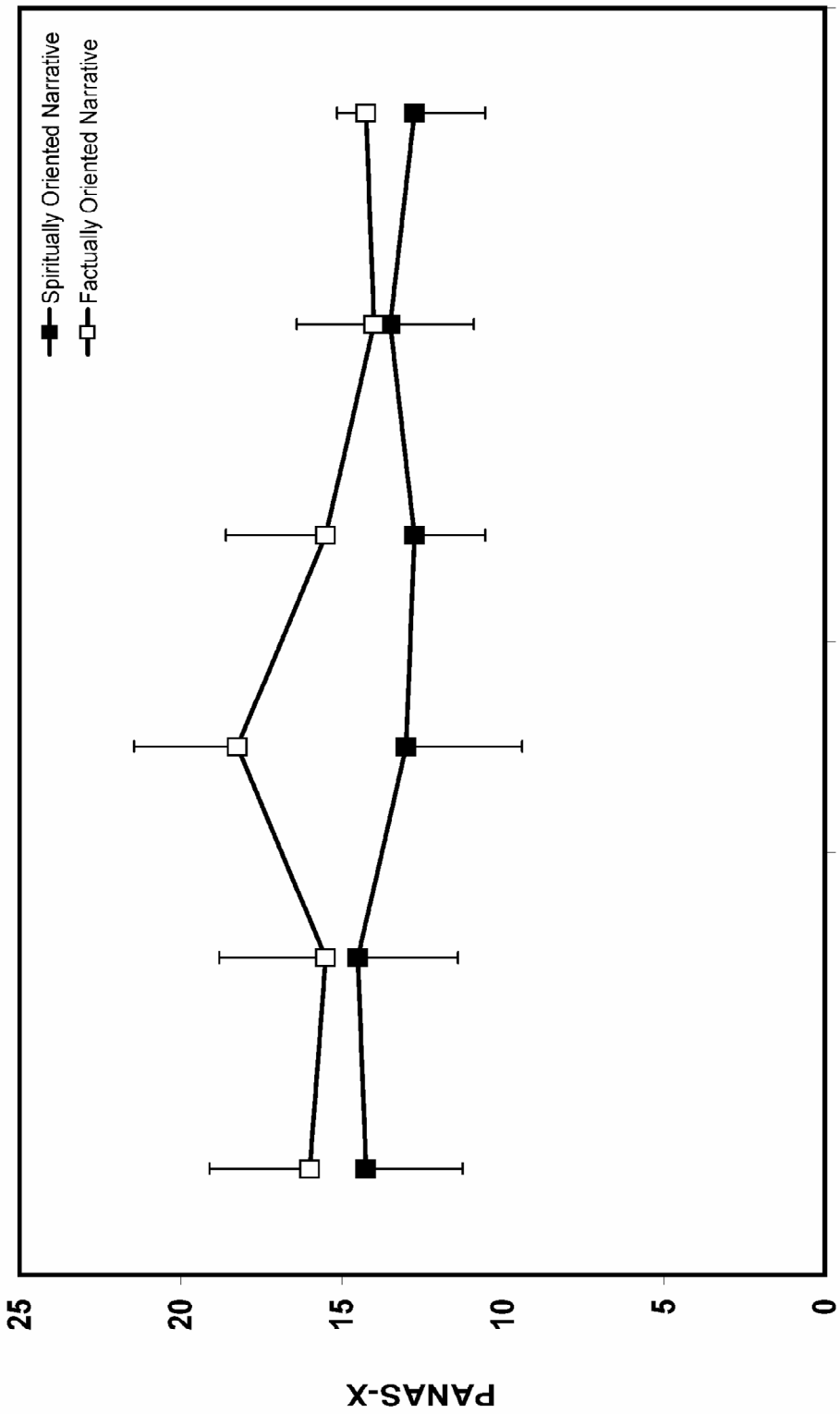


Figure 16. Weekly negative affect scores measured by PANAS-X.

The PANAS-X is also comprised of nine subscales. Each of the subscales can be used independently. Each subscale was studied as a function of the week of intervention, and the following emotions are shown in the indicated figures: fear (figure 17), hostility (figure 18), guilt (figure 19), sadness (figure 20), joviality (figure 21), self assurance (figure 22), attention (figure 23), shyness (figure 24), fatigue (figure 25), serenity (figure 26), and surprise (figure 27).

No significant differences were noted among the subscales, although it appeared that the self assurance score in both groups improved weekly, and the fatigue scores worsened weekly.

Previously, Cole (Cole et al. 2006) reported a strong correlation between the PANAS-X and the STS. In contrast, the weekly interventions had no significant effect on the PANAS-X scores. The increased fatigue seen on the PANAS-X scale was not evident on the FACT scale. The FACT is more specific for chronic illness such as cancer. However, emotional well-being was seen at week three in the FON group. The significance, if any, of this is unknown. The meaning and purpose score in both arms seems to slowly increase weekly, and the faith score of the SON arm does likewise, but the faith arm of the FON decreases. The continued decrease in faith score, although not statistically significantly, is one of the few trends noted in the weekly analysis. Only additional patients will tell if this is meaningful.

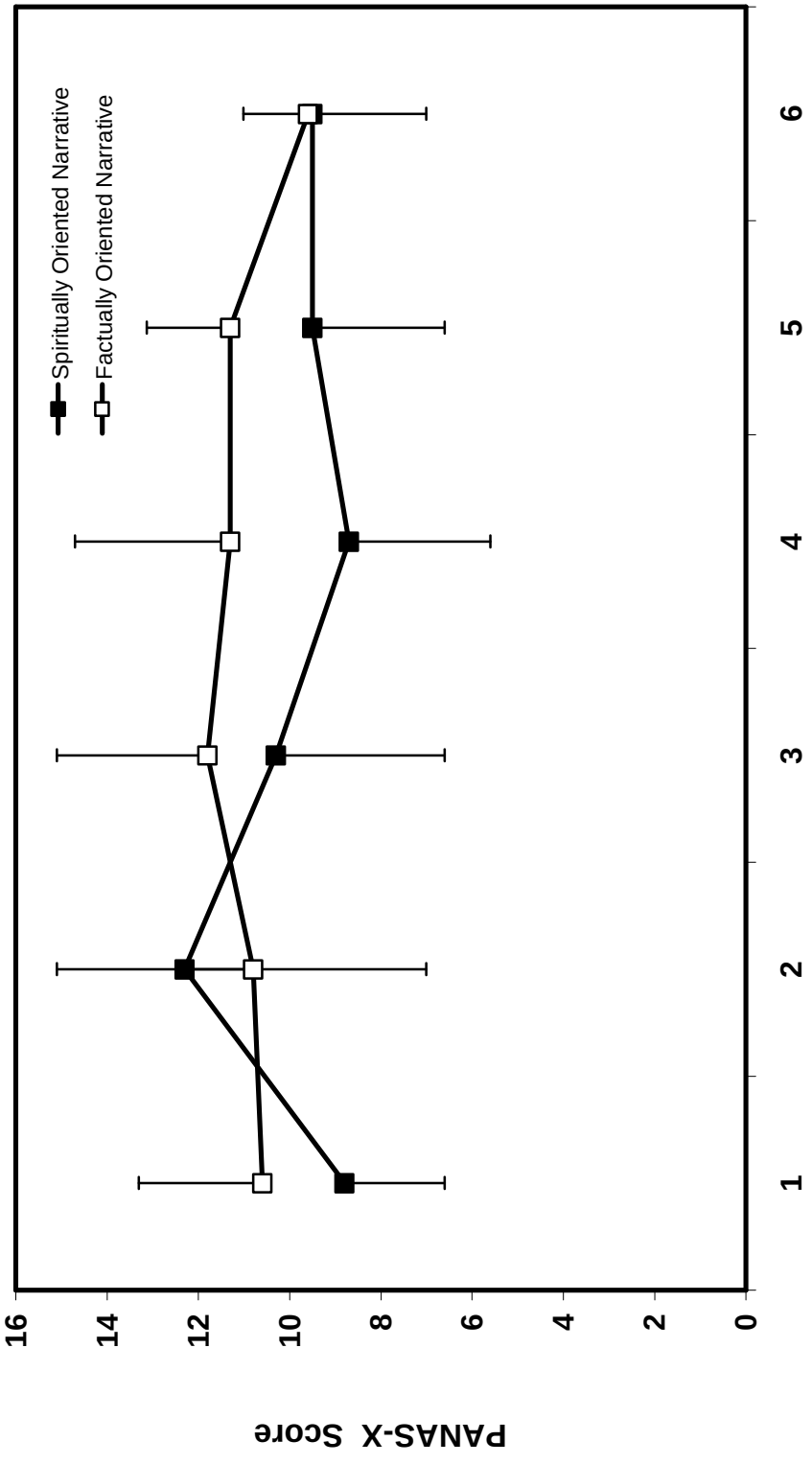


Figure 17. Weekly fear score.

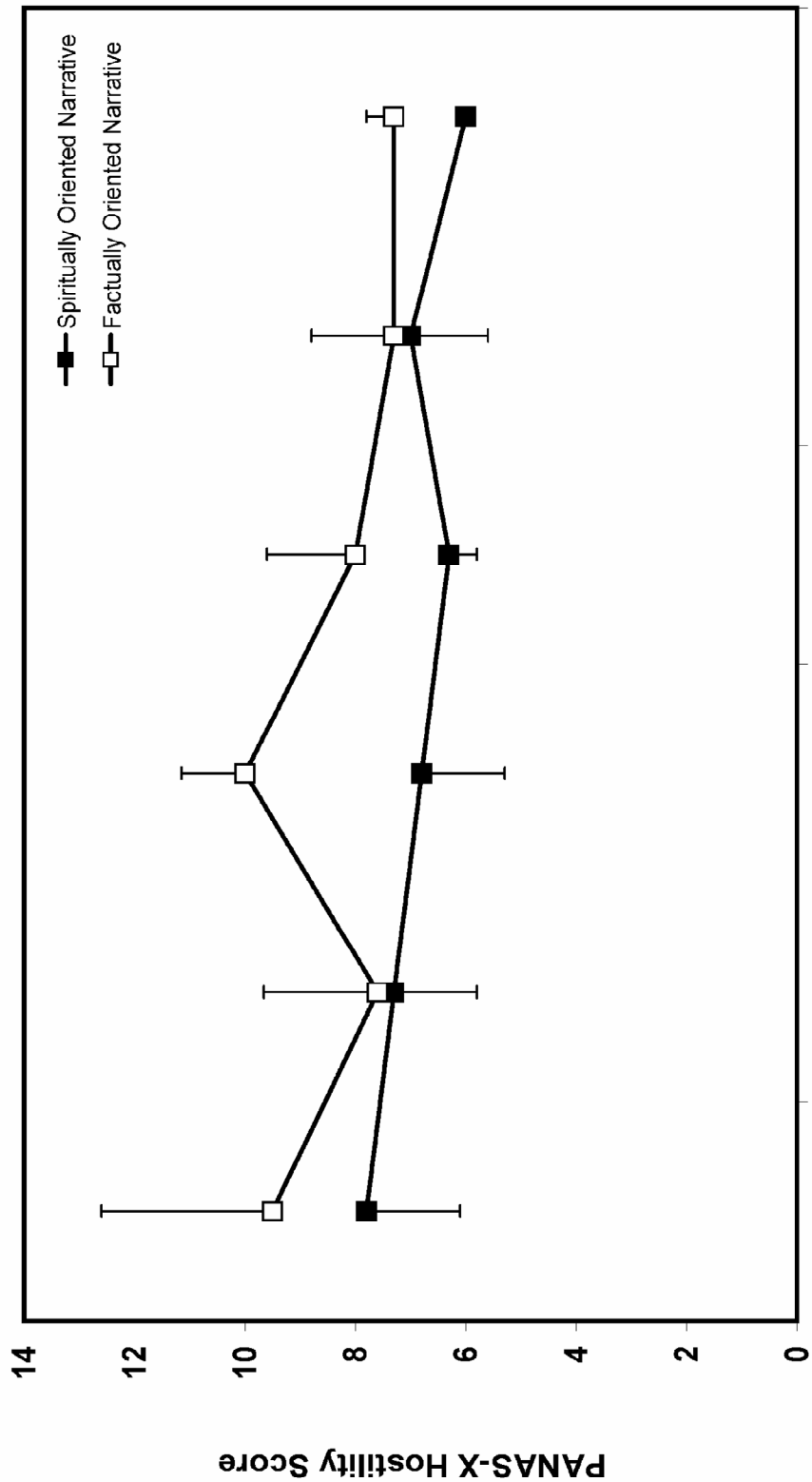


Figure 18. Weeky hostility scores.

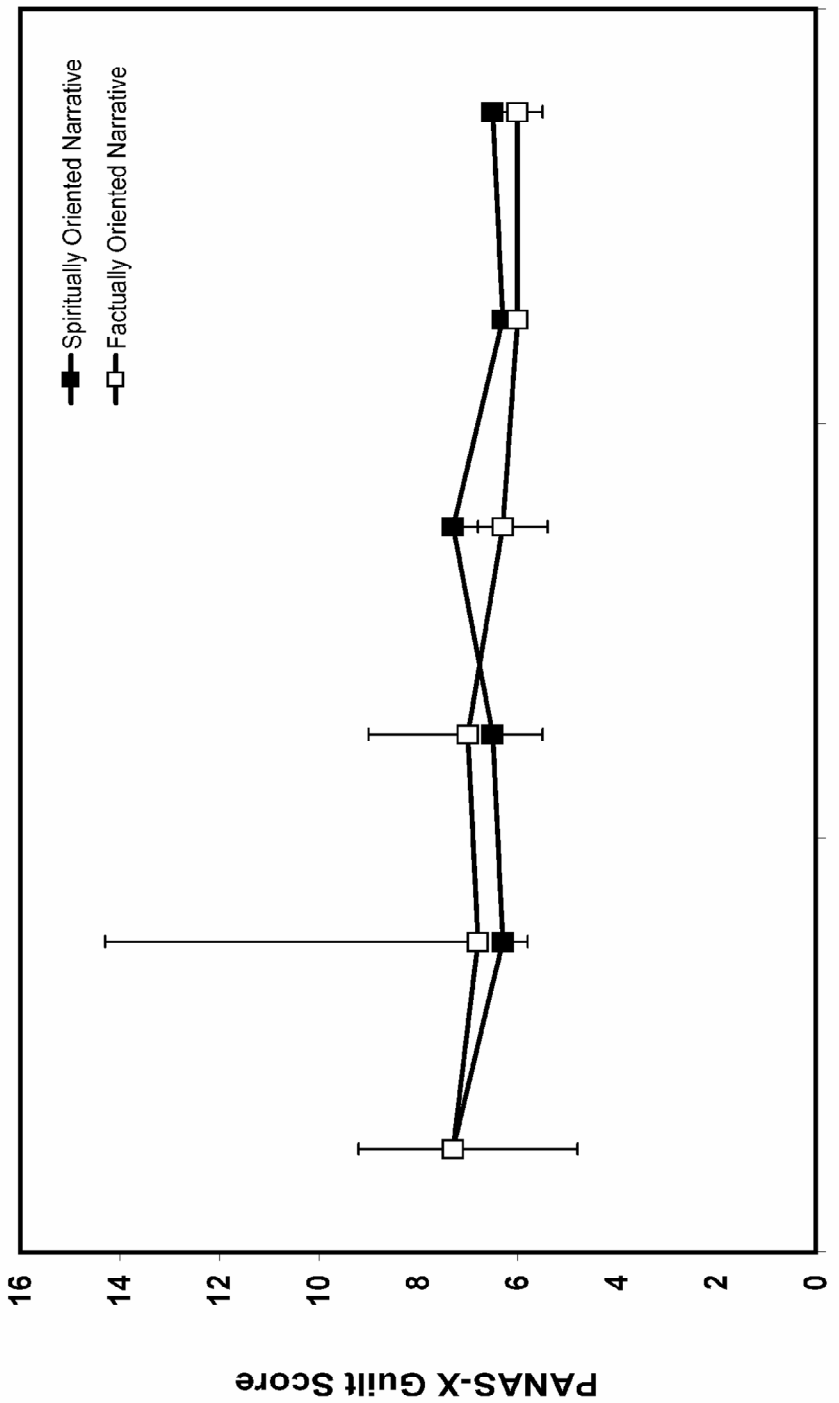


Figure 19. Weekly guilt score.

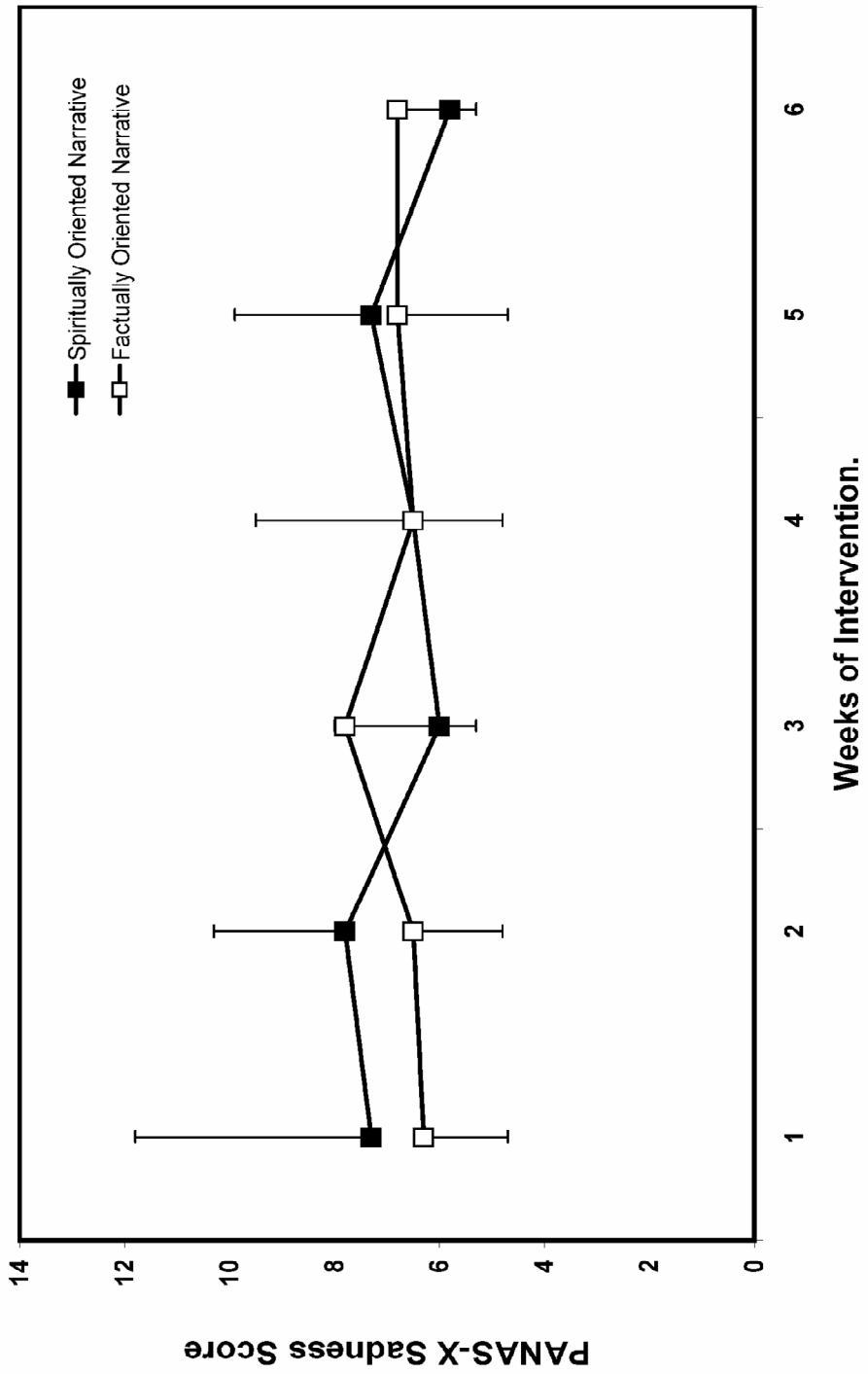


Figure 20. Weekly sadness scores.

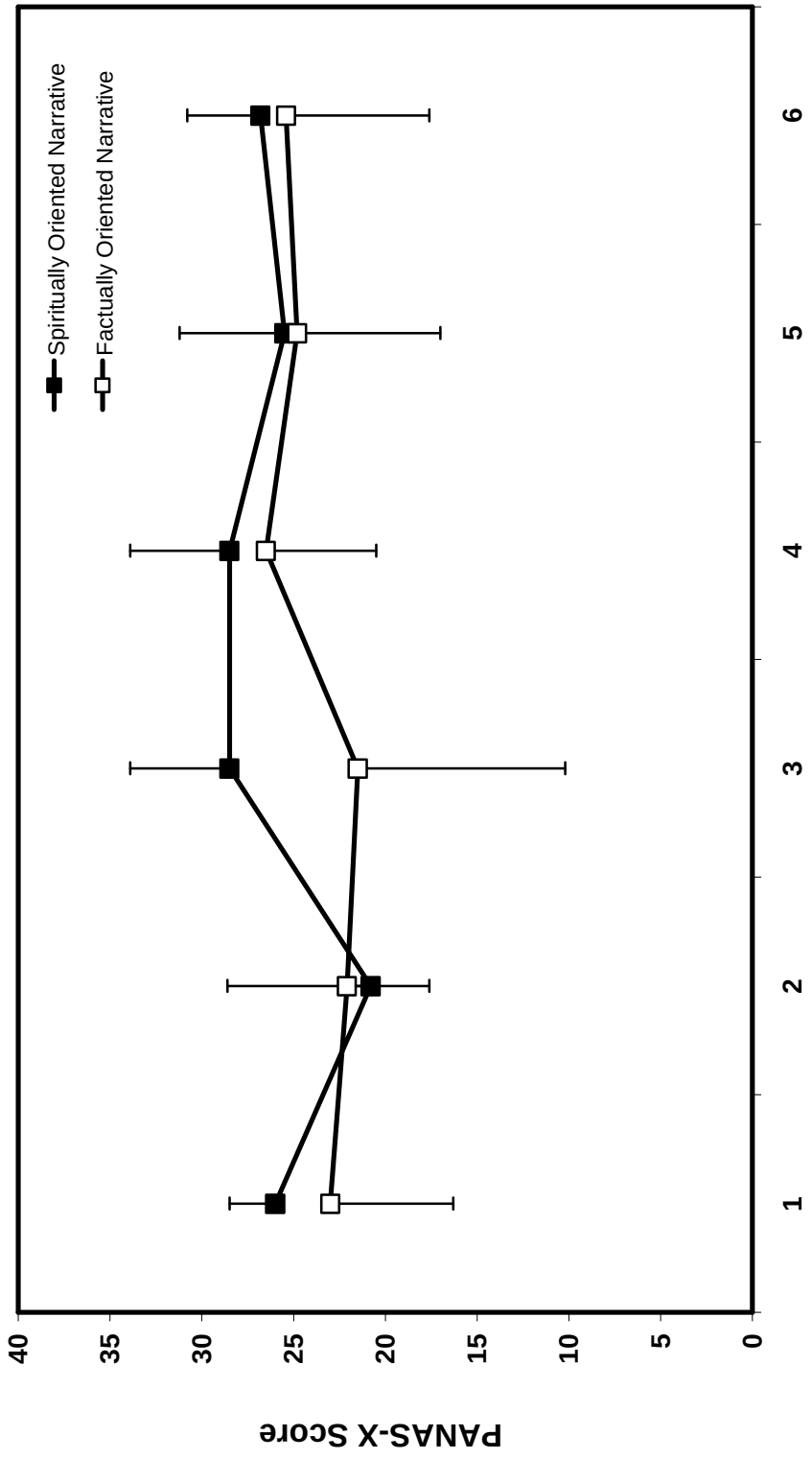


Figure 21. Weekly joviality score.

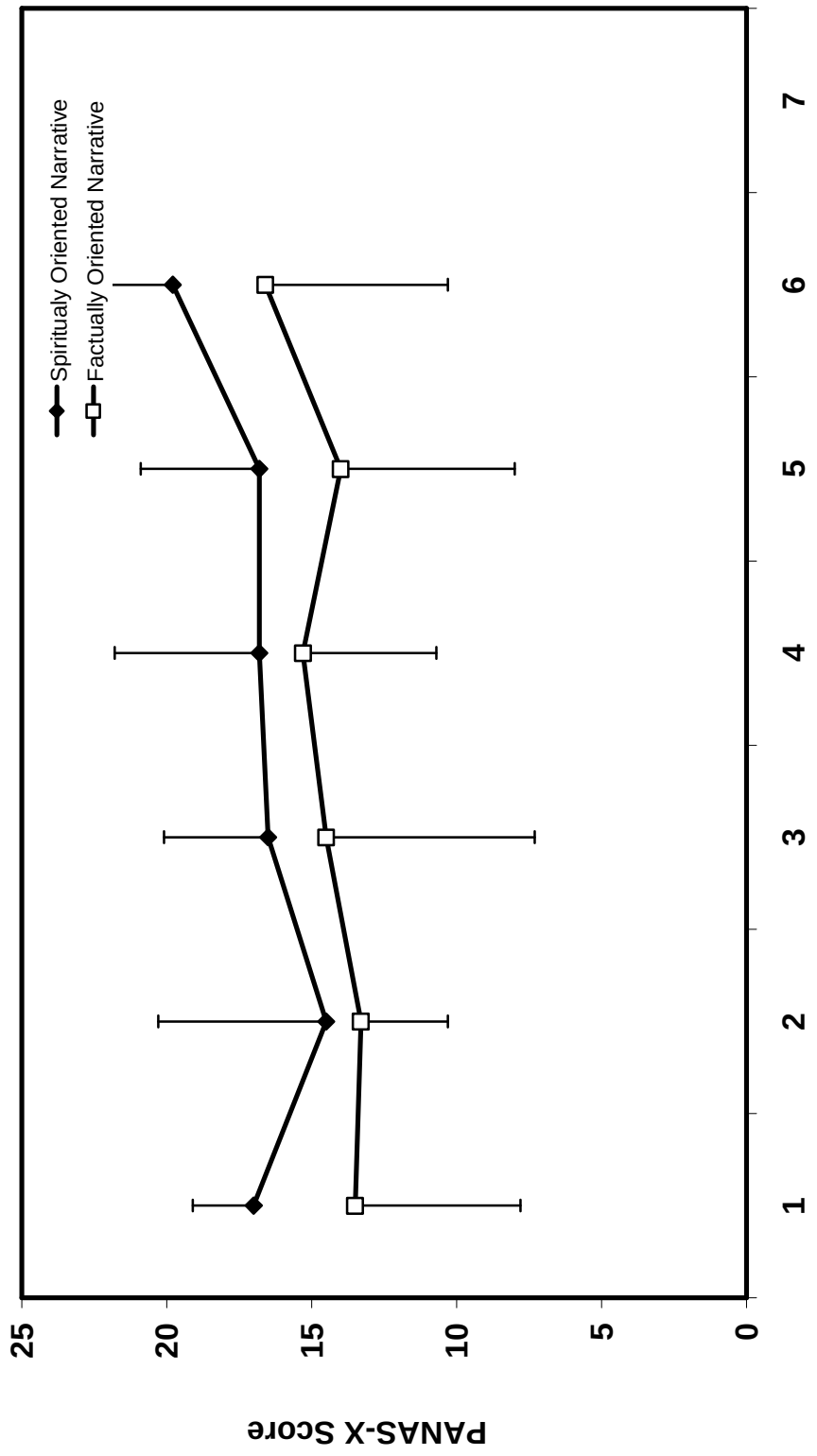


Figure 22. Weekly self assurance score.

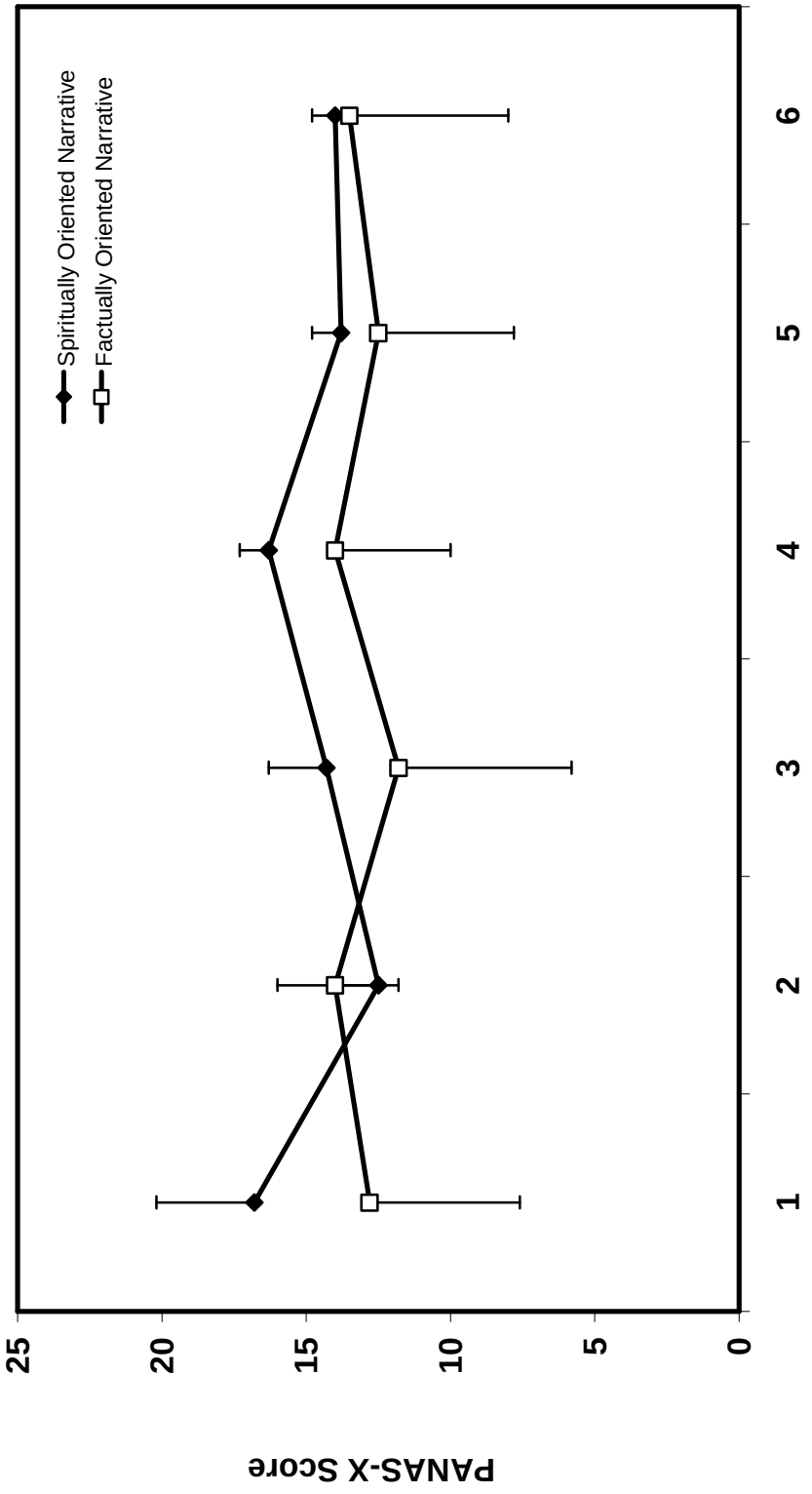


Figure 23. Weekly attention score.

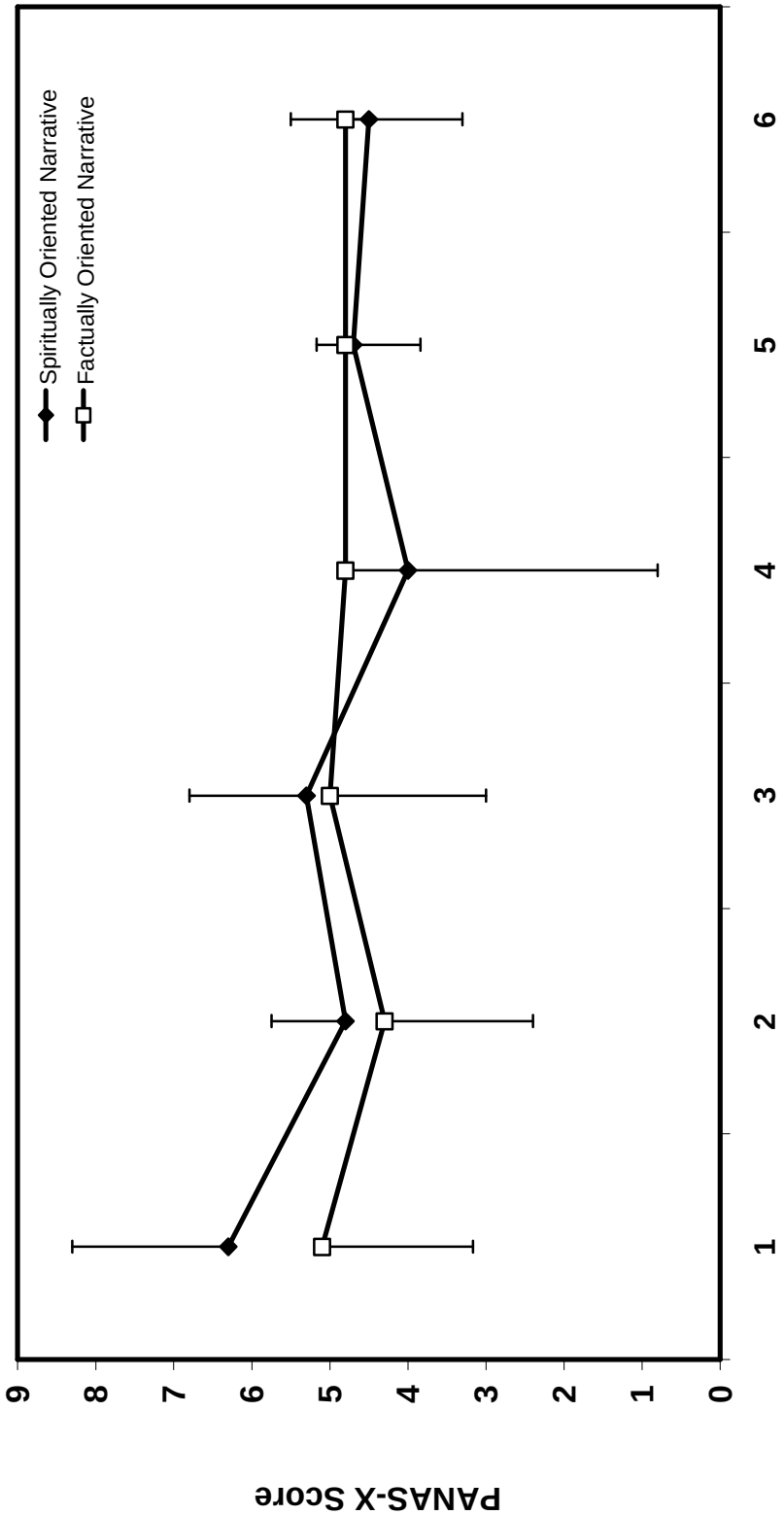


Figure 24. Weekly shyness score.

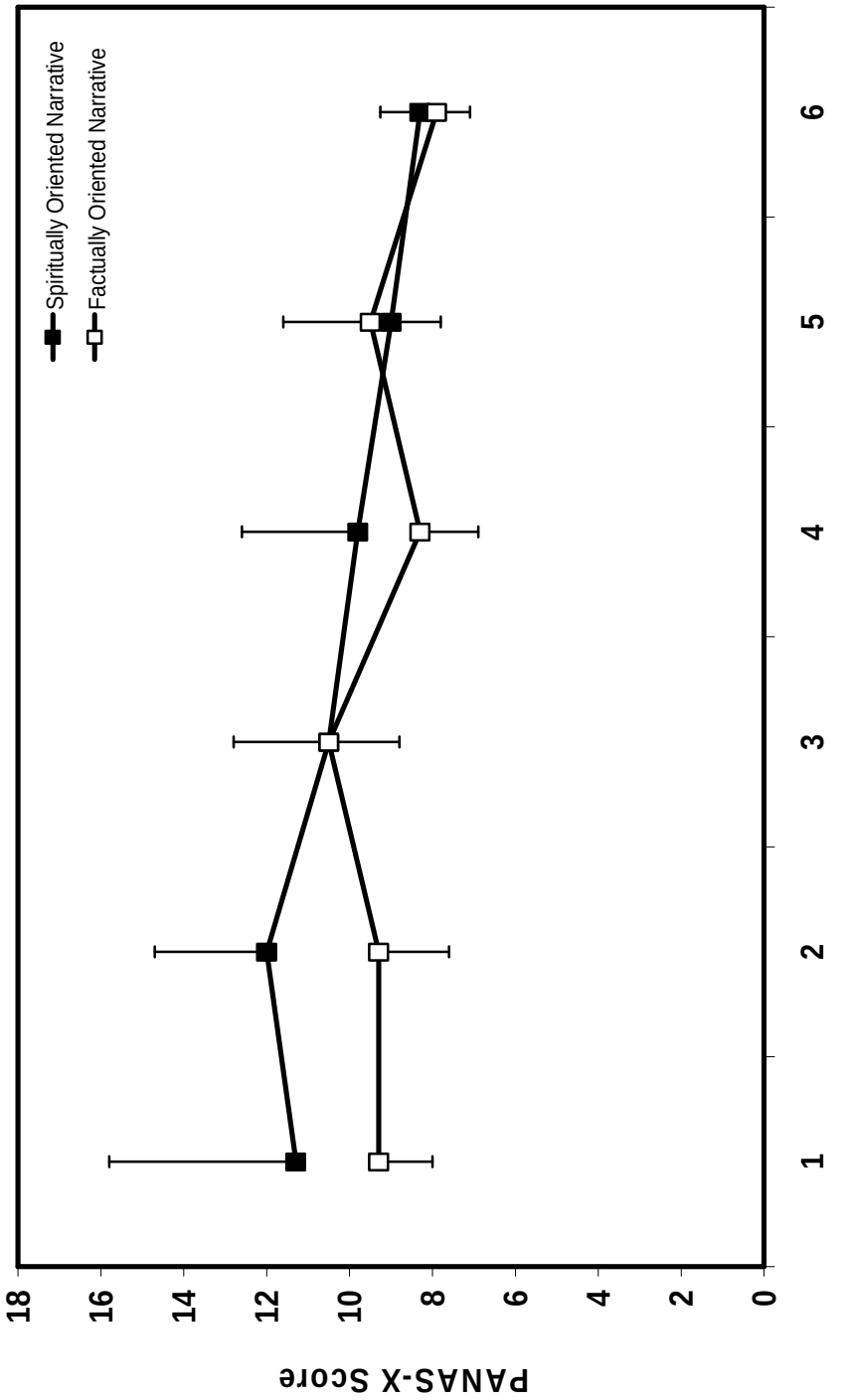


Figure 25. Weekly fatigue score.

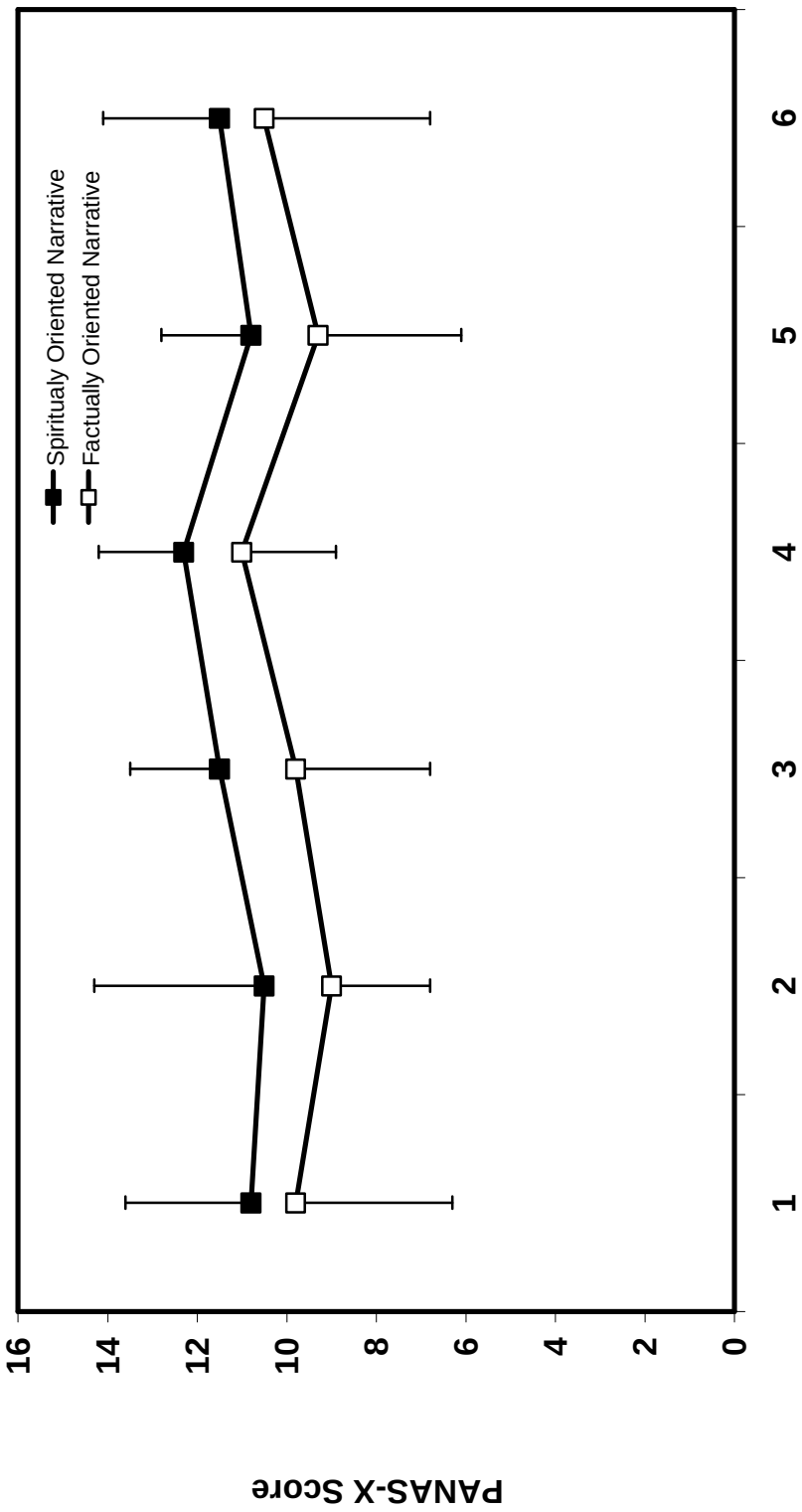


Figure 26. Weekly serenity score.

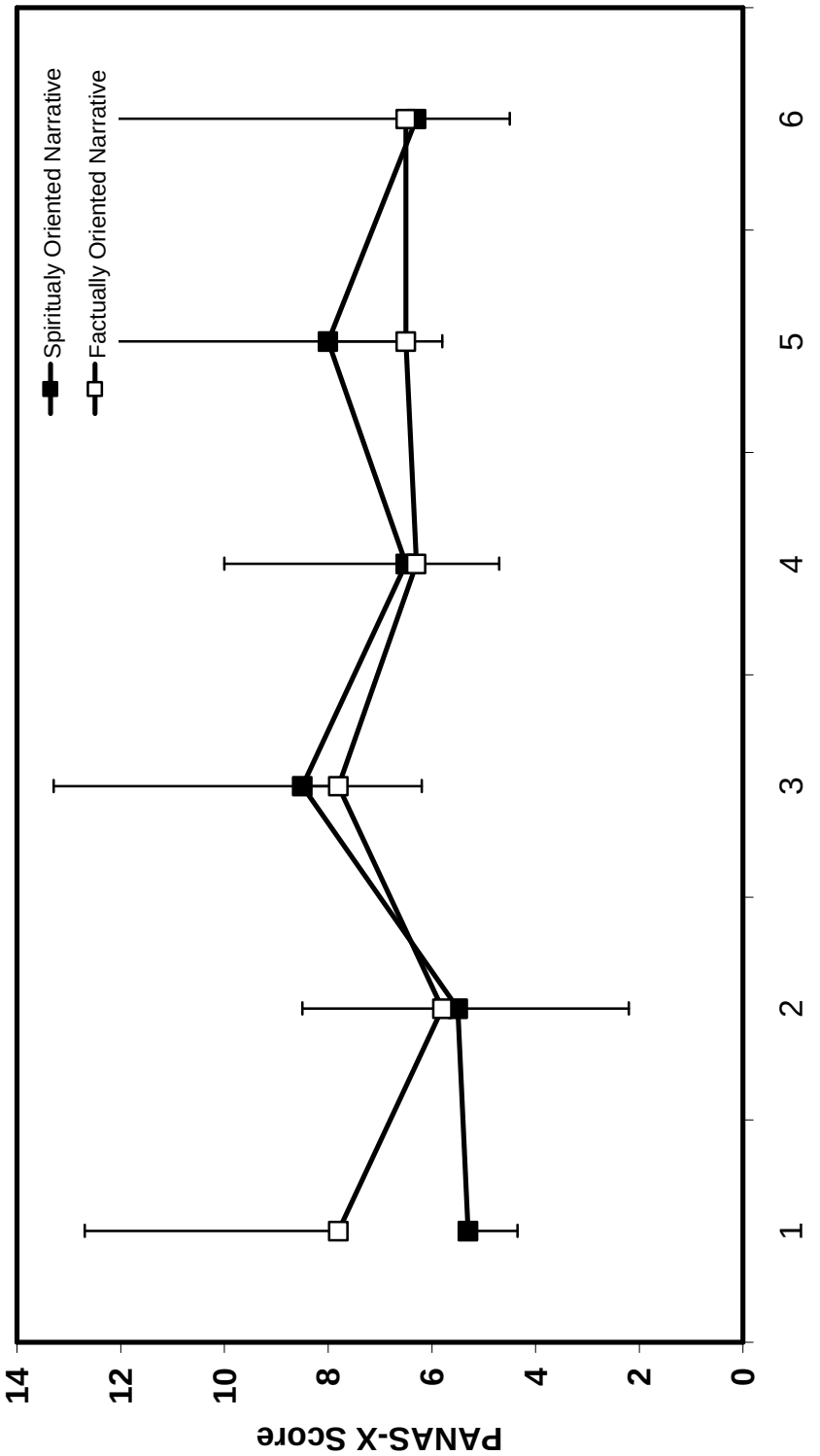


Figure 27. Weekly surprise score.

Functional Assessment of Cancer Therapy

The functional assessment of cancer therapy was done by the standard FACT (Functional Assessment of Chronic Illness Therapy) Measurement System which is a collection of health-related quality-of-life questionnaires. In this study we used the FACT-G and the FACIT-Sp tools. The FACT-G consists of 27-questions divided into four quality of life domains: physical well being, social/family well being, emotional well-being, and functional well-being. It has been shown to be appropriate for use with patients with any form of cancer (Webster et al. 2003). The FACIT-Sp consists of two subscales: the meaning and purpose and the faith subscale consisting of eight and four questions each, respectively. The inclusion of spirituality in quality- of-life measurement for oncology was demonstrated previously (Brady, 1999) and was shown to be equivalent to physical well-being in association with quality of life.

The weekly physical well being score is shown in figure 28, the social/family well being in figure 29, the emotional well-being in figure 30, and the functional well-being in figure 31. These scales are independent of church attendance and daily spiritual experiences, and the two groups are essentially identical.

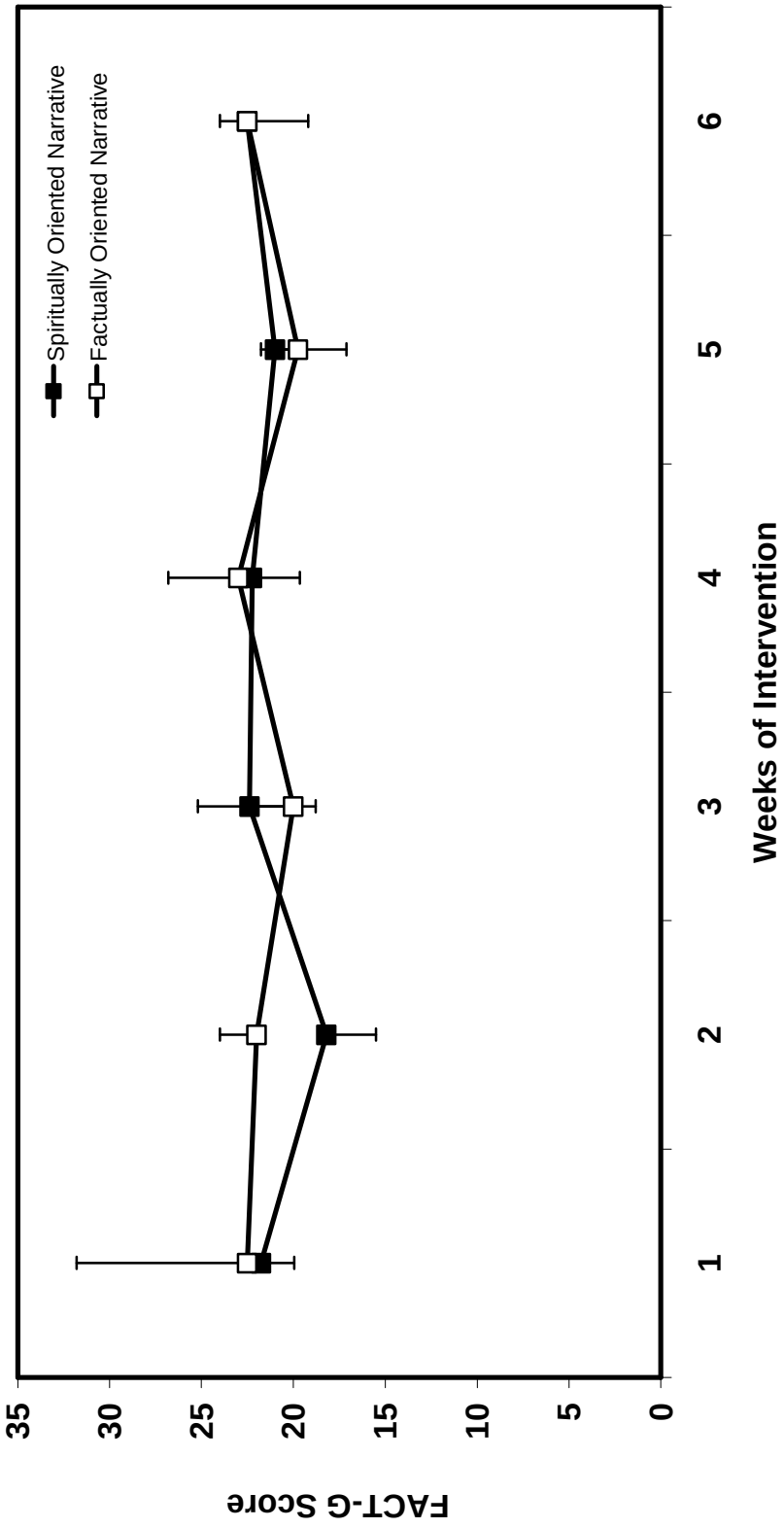


Figure 28. Weekly physical well being score.

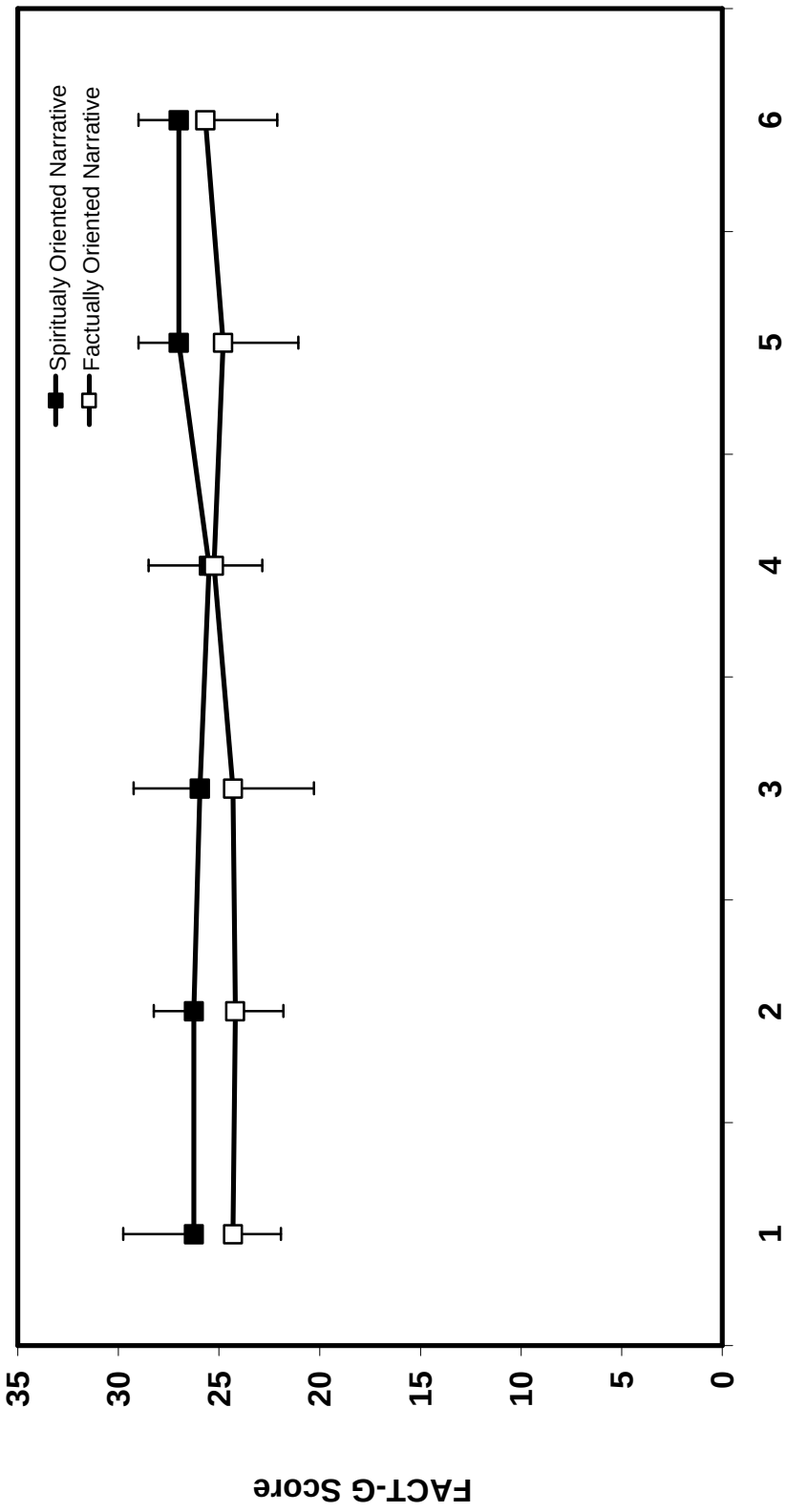


Figure 29. Weekly social well being score.

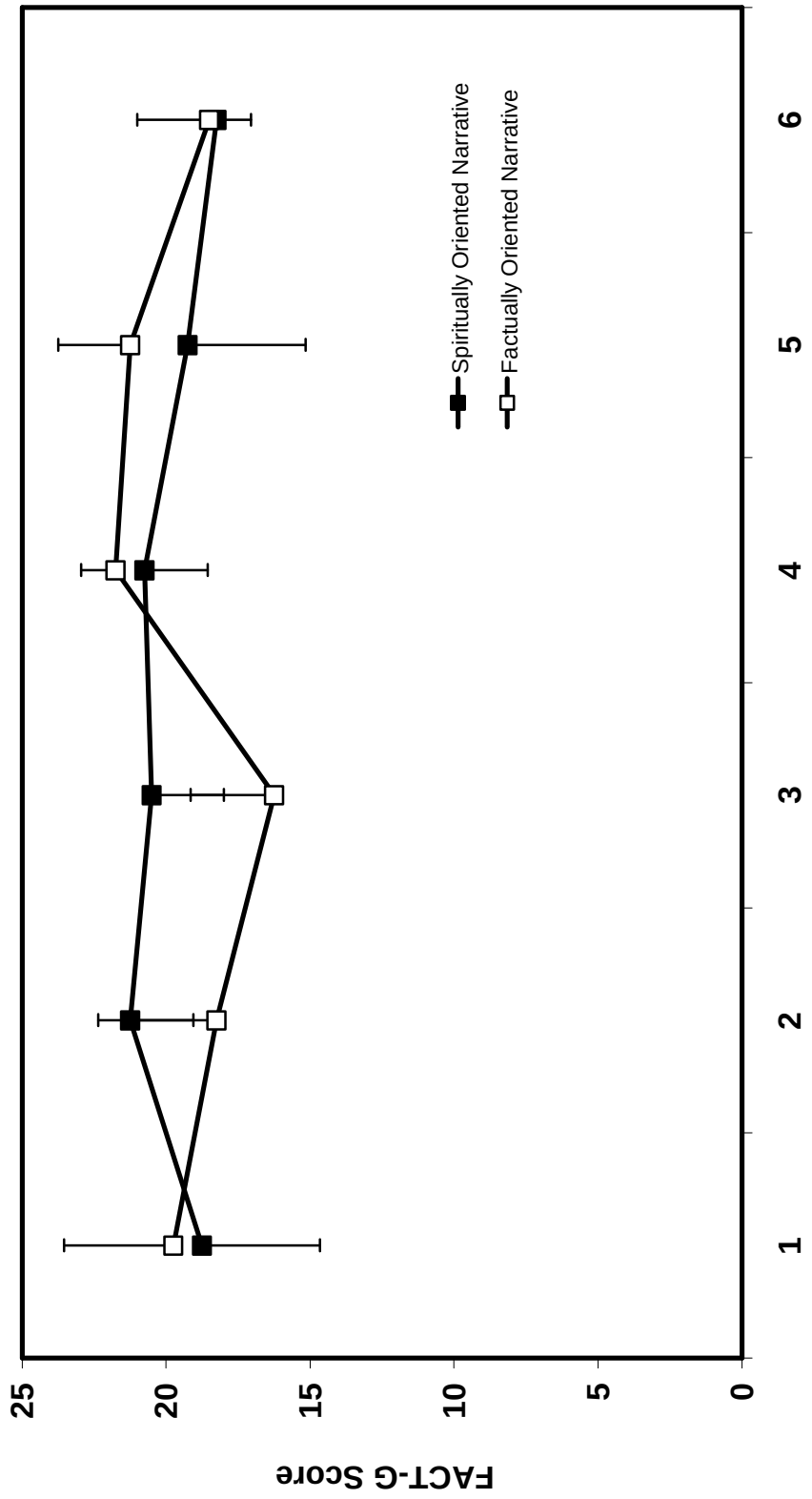


Figure 30. Weekly emotional well-being.

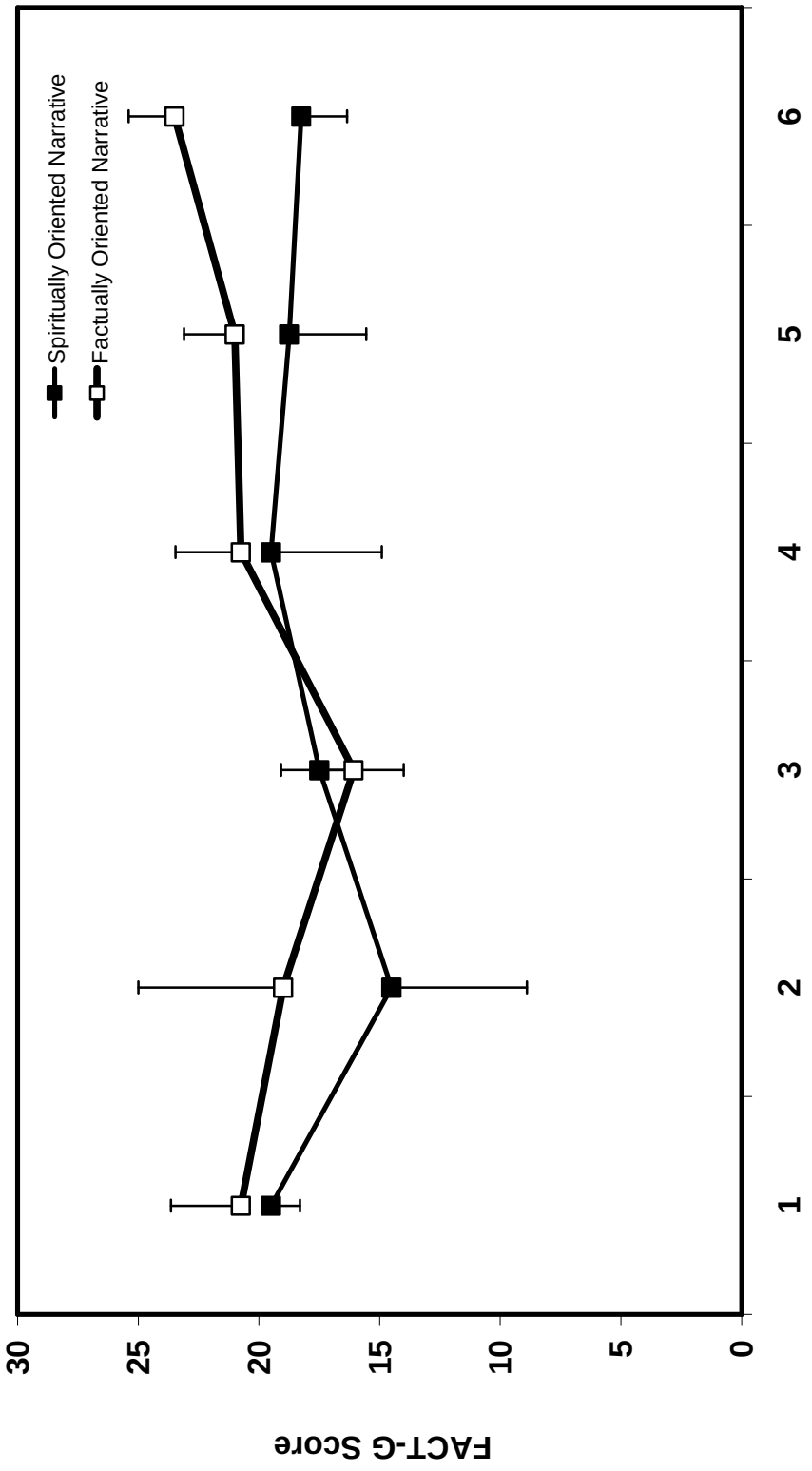


Figure 31. Weekly functional well being.

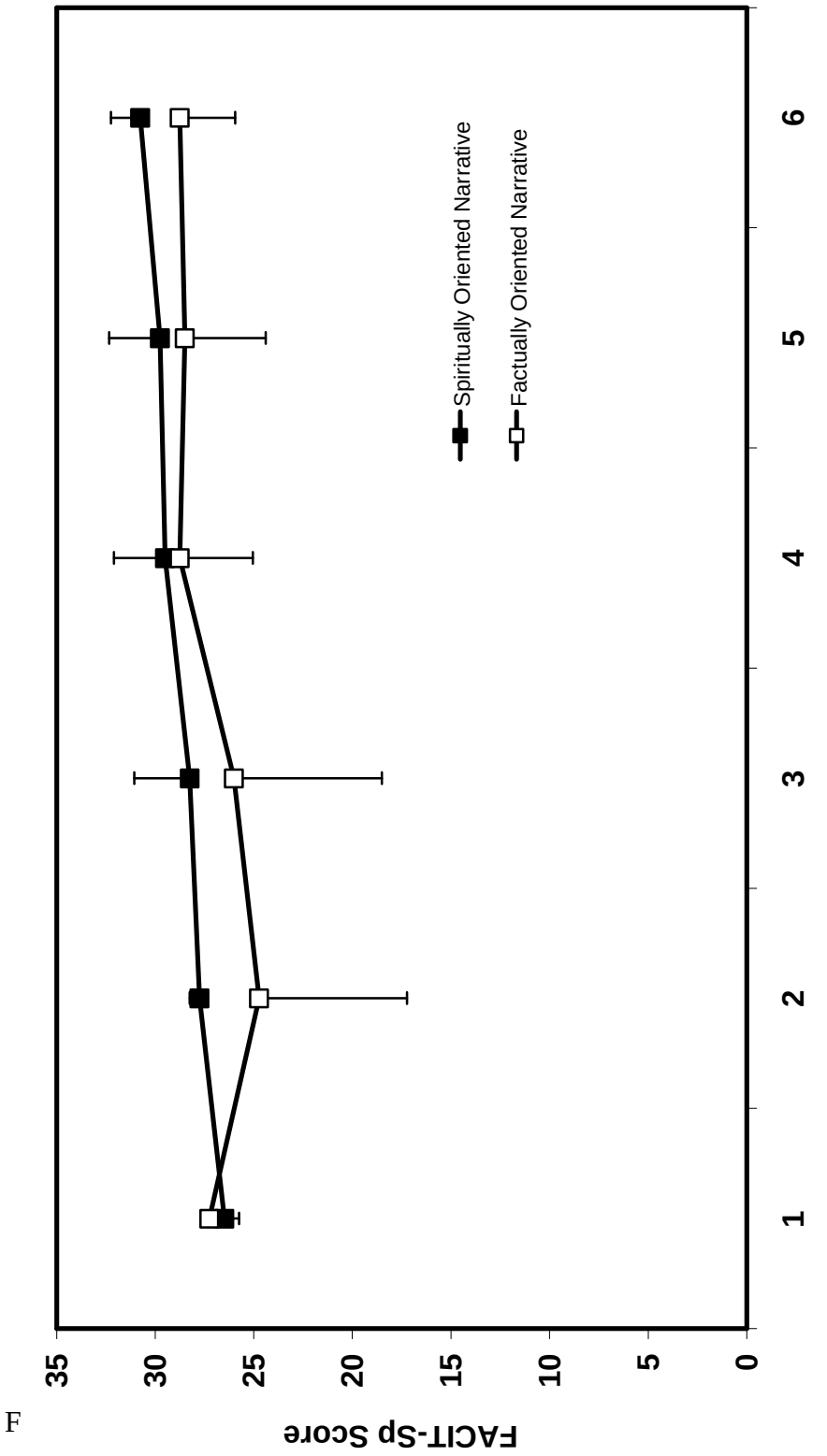
Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being

The FACIT-Sp has two subscales. Weekly measures of the meaning and purpose are shown in figure 32, and faith is shown in figure 33.

The two groups are similar with respect to meaning and purpose but differ with respect to faith, primarily due to the response of one individual. The FACIT-Sp has been shown to be effective across a range of religious tradition, including those individuals describing themselves as spiritual but not religious. Another strength of the questionnaire is that the faith subscale has a moderate to strong association with religion, and the meaning and peace subscale is not significantly associated with religion. This is readily apparent in our small population in which one non-religious individual had no influence on the average of the meaning and peace subscale but influenced the faith subscale significantly.

Spiritual Transformation Scale

The overall objective of the study was to determine if the weekly interventions had an influence on the results of the Spiritual Transformation Scale (STS) developed by Cole (Cole et al. 2006). The STS was administered one and five weeks after the completion of the interventions. The SON group demonstrated an increase in spiritual growth ($p = 0.05$) and a decrease in spiritual distress (not significant) compared to the control group,



F

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Figure 32. Weekly meaning and purpose.

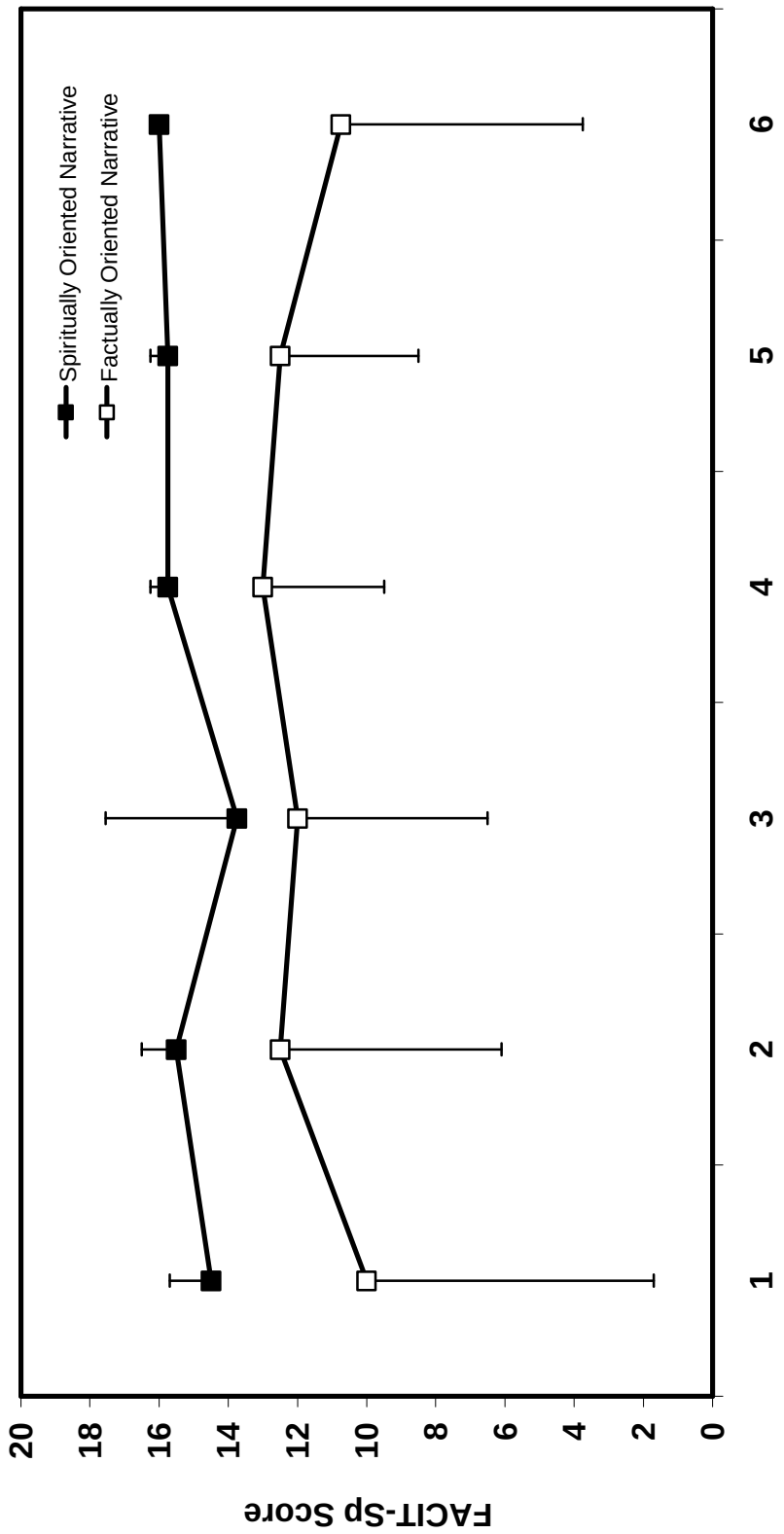

Figure 33. Weekly faith score.

and the changes held true six weeks after the last video was watched. The results are shown in Table 8.

Table 8

Spiritual Transformation Scale Scores after Intervention

Time after intervention	SON	FON
7 weeks		
Spiritual growth	6.2 (0.5)	3.0 (2.3)
Spiritual decline	1.5 (0.4)	1.7 (1.3)
12 Weeks		
Spiritual growth	6.2 (0.3)	3.4 (2.4)
Spiritual decline	1.4 (0.3)	2.8 (1.4)

Value in parenthesis is SD.

The STS consists of forty questions and is scored from one (never or not true for me) to seven (true for me a great deal of the time) as to the extent each statement is true for the patient since their diagnosis of cancer. Clearly, the SON group experienced a much greater score on the STS than did the FON group. Cole (Cole et al. 2006) provides the only comparative data in a group of 253 individuals diagnosed with cancer in the

previous two years, and reported that the spiritual growth score of the STS was 3.76 (SD = 1.70). In the same group of patients the spiritual decline score was 1.46 (SD = 0.74).

While the sample size is limited the spiritual growth score of the control arm (FON) is similar to the previous reported group of cancer patients (Cole et al. 2006), possibly indicating that intervention of a factual nature had no influence at all on spiritual transformation. The six weeks of intervention with spiritually oriented material derived from peer patient narratives appears to have increased the spiritual growth score from to 3.0 (SD = 2.3) to 6.2 (SD = 0.5) and the spiritual decline 1.7 (SD = 1.3) decreased to 1.5 (SD = 0.4). The data is skewed somewhat however for the FON arm in that two patients did not believe themselves capable of being transformed or changed because of any intervention. Out of interest, if these two are given the values of the average and the value of spiritual growth recalculated then the control arm value becomes 3.5, and the SON group would continue to demonstrate a significant increased value of STS.

Completion of Study Questionnaire

The literature is replete with debate, discussion, and comment relating to physician and issues of spirituality. Although the physician directed this study, there was a conscious effort to avoid discussions of a spiritual nature with any of the study patients. A questionnaire was designed prior to the initiation of the study with the purpose of examining some of the questions that frequently arise, such as: (1) should physicians address spiritual issues with patients? (2) Should physicians discuss spiritual concerns with patients? (3) Should Physicians refer to patients to the clergy or other specialists? (4)

Should physicians pray for their patients? (5) Should physicians initiate prayer with their patients?

The majority of the participants (7/8) preferred that the physician assess spiritually just like any other aspect of their health; only one preferred not to discuss spiritual matters with the physician. This is consistent with the upper limits of data reported in the literature (Maugans and Wadland, 1991).

Seventy-five percent of the participants stated they would likely be willing to participate in another study involving religion/spirituality matters if asked to. Interestingly, the two patients who stated they would not are the same two who had a STS score of 1.0. One of these individuals, considered herself very religious, and one considered himself not religious or spiritual at all. All patients who participated in spiritual intervention videos would participate again and would recommend it to others.

The overwhelming majority (87.5 percent) of participants desired that their physician discuss religious/spiritual problems that they, the patient, bring up. Only one patient desired to be referred to someone that might deal with the problem better than the physician. Interestingly, no one choose the option of the physician suggesting the patient see his or her clergy. The significance of this is unknown but certainly has many ramifications. This may be reflected in GfK Trust Index 2006 (1 = very untrustworthy, 2 = quite untrustworthy, 3 = quite trustworthy, 4 = very trustworthy) in which the doctors were rated highest, and clergy were ranked fifth (Hofmans 2007) in trust. It may be that clergy believe they need to provide answers to difficult questions, and all the patients are not looking for is emotive support.

Although there is much discussion regarding the ethics of physicians praying with and for their patients, there was consensus regarding this question among the patients. One participant indicated that physicians should only pray for patients if patients ask them, and seven indicated that physicians should pray for patients if the physician feels like he/she should pray for the patient. No one maintained the view that physicians should not pray for patients, even the patient self-described as having no religious experiences, no faith, and no spirituality. All participants were in agreement that sometimes it was acceptable for a physician to engage in religious/spiritual discussions with patients. The answer to this question would vary across geographic and cultural boundaries. However, when debating ethical issues, it is paramount that allowances be made for cultures and societies in which the physician offering to pray for and with a patient, and the patient being receptive to such actions, are sanctioned and indeed encouraged when the well-being of the patient and/or family is involved. An astute physician is always aware of the time when the art of medicine is practiced and perhaps even prayerfully aware.

The patients had no difficulty in physicians' initiating the lead about spiritual matters. This was a unanimous choice in both groups.

The majority of patients did not experience any spiritual concerns during their treatment time (7/8). When asked about their source of support if they had had any concerns, 5/7 patients listed their family, 1/7 listed church/clergy and 1/7 listed self (one did not answer).

In answer to the question about what they would have welcomed during their diagnosis and treatment, the majority chose discussion by their doctor (5/8). One chose

referral to a support group, two chose the choice “other,” and no one chose “referral to a minister”.

The time of participating in a study aimed at improving spirituality was not critical. Fifty percent of the patients said it did not matter, and only one said after work. Thus, if the study is during office hours about 87 percent of the patients are pleased.

The answer to the question: “Do you think the 5 minute video about the story of another cancer patient was helpful to you?” was split down study lines. Everyone in the spiritually oriented arm said yes, and everyone in the factually oriented arm said no. This is the same group in which 50% said they would not participate in another such study. In reference to the video, all patients did not think the video in any way threatening to their current faith, and only 25 % thought it might be improved by providing a copy to take home. Half the patients thought that having Bible verses associated with the narrative might be helpful, and only 1/8 thought background music would be helpful. Fifty percent thought family members should have the opportunity to watch, and 3/8 thought their clergy should be provided a copy to review.

The majority of the patients in the SON group described positive emotions while watching the videos. For example: comforted (4/4), uplifted (4/4), peaceful (4/4), loved by God (4/4), and loved by people (4/4). The corresponding numbers for the FON group were (2/4), (2/4), (1/4), (2/4), (2/4).

Three-fourths of the patients indicate they believe it would be helpful if our office provided a resource area aimed at meeting emotional and religious needs, and half said they would make use of a quiet place set aside for prayer and meditation.

There was little interest in having a chaplain or pastoral care team available (1/8) probably reflecting the heavy churched area in which we live.

Fifty percent of the patients stated they had felt the need to become more religious or spiritual since their diagnosis. Interestingly, three of the four are from the SON group.

Impact of Current Study on Ministry

The study was not designed to impact healthcare per se, yet it has done just that. It has resulted in an increased awareness of the need for an area within our office to facilitate spiritual awareness.

The study was designed to determine the efficacy of spiritually oriented narrative intervention (SON) compared to factually oriented narrative intervention (FON) in patients newly diagnosed with cancer. The intervention was developed around narrative stories of previous cancer patients that had undergone chemotherapy treatment and had, in the opinion of the author, undergone a transformative experience. While numerous interventions have been developed around various themes to enhance coping and decrease distress, these are usually written by the therapist. Based on the often heard adage, “you can’t know how feel until you’ve walked in my moccasins,” the author choose to use the words of the patients in developing the interventions in the form of a brief story about the individual’s life.

One difficulty with such studies is the proper control group. Randomization is difficult in a small office in which patients may communicate during treatment about the

videos they have seen. The control group in this study consisted of another medical oncology office in which the author works and which operates with the same policies and procedures and with some of the same staff. Now that preliminary data is complete, the process of such randomization may be a moot point since the standard of care may be to provide a spiritually oriented intervention. Further study then would be to determine additional ways that might improve the efficacy of the intervention.

The current study underway with a decreased amount of testing will help in answering this question and will seek an additional 20 patients in each group. The stringent criteria of 28 days since diagnosis of cancer had to be modified since patients often had complications from surgery or had to have another procedure that made them ineligible for the study. The modified study is such that as long as they have 12 weeks of chemotherapy remaining they are eligible for the study.

The high drop out rate was unexpected. The initial time studies gave no indication that people would find the questionnaires too difficult. However, the timed studies were taken from people not dealing with proximity to diagnosis issues; therefore, they certainly were not subjected to the same stress issues. Furthermore, only one test was given to each individual when evaluating the time for completion, and the patients were being asked to complete from five to eight tests each week.

When the first ten patients in each group were evaluated, a high attrition rate was noticed. This fact, coupled with the modicum of additional information gleamed from the weekly testing, warranted a modification to the study to include testing at weeks one, seven and twelve. To date we have enrolled over 15 patients with the majority remaining in the study.

The next study will involve the following:

1. Different groups of patients representing different proximities to death. The groups will include (a) patients receiving adjuvant chemotherapy (b) patients receiving treatment for metastatic cancer (c) patients on hospice care (d) patients on follow up but 5 years free of cancer (e) patients with non life-threatening hematological diseases (f) patients receiving weekly iron infusions.

2. Since it is impossible to blind this study the groups will be crossed over every ten patients in each arm. Thus, when ten patients have been enrolled in the SON group at one office location, the next ten will be enrolled in the FON at the same office location.

3. Family members will be studied as well. In additional to investigating spiritual growth or decline in family members, the families of cancer patients will be asked to evaluate the patient as well.

5. The baseline data collection will be simplified if the additional patients being studied indicate that no additional information is obtained.

6. Patients will be followed for up to five years to determine the permanency of this change.

7. The currently used STS may be redefined to a Christian-based measurement tool..

8. After details and logistics of the study are better known, a parallel study at a large metropolitan teaching hospital would be of interest.

Appendix A

Performance Status Scales

ECOG Performance Status Scale		Karnofsky Performance Scale	
Grade	Descriptions	Percent	Description
0	Normal activity. Fully active, able to carry on all pre-disease performance without restriction.	100	Normal, no complaints, no evidence of disease.
		90	Able to carry on normal activity; minor signs or symptoms of disease.
1	Symptoms, but ambulatory. Restricted in physically strenuous activity, but ambulatory and able to carry out work of a light or sedentary nature (e.g., light housework, office work).	80	Normal activity with effort; some signs or symptoms of disease.
		70	Cares for self, unable to carry on normal activity or to do active work.
2	In bed <50% of the time. Ambulatory and capable of all self-care, but unable to carry out any work activities. Up and about more than 50% of waking hours.	60	Requires occasional assistance, but is able to care for most of his/her needs.
		50	Requires considerable assistance and frequent medical care.
3	In bed >50% of the time. Capable of only limited self-care, confined to bed or chair more than 50% of waking hours.	40	Disabled, requires special care and Assistance.
		30	Severely disabled, hospitalization indicated. Death not imminent.
4	100% bedridden. Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair.	20	Very sick, hospitalization indicated. Death not imminent.
		10	Moribund, fatal processes progressing rapidly.
5	Dead.	0	Dead.

Appendix B

Informed Consent

Study Identification No.

___-____

SPIRITUALITY IN INDIVIDUALS DIAGNOSED WITH CANCER: INTERVENTIONAL STORYTELLING UTILIZING PEER PATIENT NARRATIVES

J. Patrick Daugherty MD, PhD, Principal Investigator

Larry Bates, PhD, Co-Investigator

Informed Consent Form

for

Spirituality in Individuals Diagnosed with Cancer: Interventional Storytelling Utilizing Peer Patient Narratives

You are being invited to participate in a research study because you have been diagnosed with cancer and some studies have shown that information provided to patients may help them cope with their diagnosis. Some of the information is spiritually focused

and some is not. The information is derived from the life stories of patients that have been diagnosed and treated for cancer. The purpose of the study is to gather information on ways to improve coping associated with the diagnosis of cancer, and to gather information on the effectiveness of these interventions.

If you decide to participate, we (Dr. J. Patrick Daugherty and Dr. Larry W. Bates) will ask you to complete several questionnaires regarding the impact of your diagnosis of cancer on your quality of life (physical, emotional and spiritual) at the beginning of your chemotherapy, every week during athe six-week intervention, and six and eighteen weeks afte the competion of the intervention. You may also be asked to answer a few questions in an interview about how you viewed the study and the use of interventional material and the possible value of the study to you. It is estimated that it will take less than 30 minutes to complete the questionnaires and the interview

There are no known personal benefits to you other than potentially gaining new insight into your reaction to the diagnosis of cancer. You may or may not experience improved coping with your cancer because of the interventions. However, the information you provide may help in improving treatments for patients with dancer in the future. However, we cannot promise you will receive any or all of these benefits. We do not expect this research to pose any risk to the volunteer participants and you should experience no more stress in this research than you normally would when discussing your cancer diagnosis, its treatment and side effects.

Your participation in this study is voluntary. You may withdraw from the study at any time. Your decision of whether to participate will not prejudice your future

relations with Northwest Alabama Cancer Center or the University of North Alabama or the department of psychology.

If you give us permission by signing this document, the data you provide will be used only for the purposes of preparing scientific reports. We will never include your names on any of the forms containing information about you and will instead use code numbers to protect your anonymity. Under no circumstances will we identify the individuals who participate in the study in reports of the study.

This research has been approved through the University of North Alabama (Florence, Alabama), Human Subjects Committee. If you have any questions, please feel free to call or email, Dr. J. Patrick Daugherty or Dr. Larry Bates at Northwest Alabama Cancer Center (256-764-4200; 256-381-9090; cancerdoc@yahoo.com) or at the Department of Psychology, University of North Alabama (256) 765-4712, (256)765-4390, or lwbates@una.edu, , and we will be happy to answer them

I understand the above and agree to participate.

_____

Name (please print clearly)

_____ _____

Participant's Signature Date

Appendix C

Data Element Collection Schedule

Item	Wks of Intervention						Post Intervention	End of Treatment
	1	2	3	4	5	6		
Informed Consent	X							
PT demographics	X							
Vital Signs	X	X	X	X	X	X	X	X
Clinical status	X	X	X	X	X	X	X	X
Cancer Status								X
BMMRX	X							
ROS	X							
FACT-G	X	X	X	X	X	X		
CES-Depression	X	X	X	X	X	X		
PANAS			X			X		
FACIT-Sp-12	X	X	X	X	X	X		
STS							X	X
DSE	X	X	X	X	X	X		
Intervention Survey								X

Appendix D

Demographic Information

Office Location: Florence _____

Muscle Shoals _____

Patient Study Number ___-___

Date of patient enrollment: _____/_____/_____ (dd/mmm/yyyy)

Patient's age at enrollment: _____years

Date patient signed informed consent: _____/_____/_____ (dd/mmm/yyyy)

Gender: Female ____

Male _____

Race: White, non-Hispanic

American Indian _____

African American or black _____

Other_ (specify) _____

Patient Contact Information: Obtain from chart

Primary cancer diagnosis: _____

Date of diagnosis: _____/_____/_____ (dd/mmm/yyyy)

TNM Staging:

Date of staging: _____/_____/_____ (dd/mmm/yyyy)

Appendix E

Clinical Data Collected Each Visit

Vital Signs: Wight _____

Temp _____

Blood pressure _____

Heart rate _____

Respiratory rate _____

ECOG and/or Karnofsky Performance Status Score _____

Nausea/vomiting

Fatigue/lack of energy

Pain level

Review of systems: fever, diarrhea, constipation, skin changes, mouth sores, night sweats, swelling, numbness, chest pain, shortness of breath

Physical examination

Any new medications:

Appendix F

Brief Multidimensional Measurement of Religiousness/Spirituality

Daily Spiritual Experiences

The following questions deal with possible spiritual experiences. To what extent can you say you experience the following?

1. I feel God's presence.

    1 - Many times a day
    2 - Every day
    3 - Most days
    4 - Some days
    5 - Once in a while
    6 - Never or almost never

2. I find strength and comfort in my religion.

    1 - Many times a day
    2 - Every day
    3 - Most days
    4 - Some days
    5 - Once in a while
    6 - Never or almost never

3. I feel deep inner peace or harmony.

    1 - Many times a day
    2 - Every day
    3 - Most days
    4 - Some days
    5 - Once in a while
    6 - Never or almost never

4. I desire to be closer to or in union with God.

    1 - Many times a day
    2 - Every day
    3 - Most days
    4 - Some days
    5 - Once in a while
    6 - Never or almost never

5. I feel God's love for me, directly or through others.

1 - Many times a day
2 - Every day
3 - Most days
4 - Some days
5 - Once in a while
6 - Never or almost never

6. I am spiritually touched by the beauty of creation.

1 - Many times a day
2 - Every day
3 - Most days
4 - Some days
5 - Once in a while
6 - Never or almost never

Meaning

1. The events in my life unfold according to a divine or greater plan.

1 - Strongly agree
2 - Agree
3 - Disagree
4 - Strongly disagree

2. I have a sense of mission or calling in my own life.

1 - Strongly agree
2 - Agree
3 - Disagree
4 - Strongly disagree

Values/Beliefs

7. I believe in a God who watches over me.

1 - Strongly agree
2 - Agree
3 - Disagree
4 - Strongly disagree

8. I feel a deep sense of responsibility for reducing pain and suffering in the world.

1 - Strongly agree
2 - Agree
3 - Disagree
4 - Strongly disagree

Forgiveness

Because of my religious or spiritual beliefs:

9. I have forgiven myself for things that I have done wrong.

1 - Always or almost always
2 - Often
3 - Seldom
4 – Never

10. I have forgiven those who hurt me.

1 - Always or almost always
2 - Often
3 - Seldom
4 – Never

11. I know that God forgives me.

1 - Always or almost always
2 - Often
3 - Seldom
4 – Never

Private Religious Practices

12. How often do you pray privately in places other than at church or synagogue?

1 - More than once a day
2 - Once a day
3 - A few times a week
4 - Once a week
5 - A few times a month
6 - Once a month
7 - Less than once a month
8 – Never

13. Within your religious or spiritual tradition, how often do you meditate?

1 - More than once a day
2 - Once a day
3 - A few times a week
4 - Once a week
5 - A few times a month
6 - Once a month
7 - Less than once a month
8 – Never

14. How often do you watch or listen to religious programs on TV or radio?

1 - More than once a day
2 - Once a day
3 - A few times a week
4 - Once a week
5 - A few times a month
6 - Once a month
7 - Less than once a month
8 – Never

15. How often do you read the Bible or other religious literature?

1 - More than once a day
2 - Once a day
3 - A few times a week
4 - Once a week
5 - A few times a month
6 - Once a month
7 - Less than once a month
8 – Never

16. How often are prayers or grace said before or after meals in your home?

1 - At all meals
2 - Once a day
3 - At least once a week
4 - Only on special occasions
5 – Never

Religious and Spiritual Coping

Think about how you try to understand and deal with major problems in your life. To what extent is each of the following involved in the way you cope?

17. I think about how my life is part of a larger spiritual force.

1 - A great deal
2 - Quite a bit
3 - Somewhat
4 - Not at all

18. I work together with God as partners.

1 - A great deal
2 - Quite a bit
3 - Somewhat
4 - Not at all

19. I look to God for strength, support, and guidance.

1 - A great deal
2 - Quite a bit
3 - Somewhat
4 - Not at all

20. I feel God is punishing me for my sins or lack of spirituality.

1 - A great deal
2 - Quite a bit
3 - Somewhat
4 - Not at all

21. I wonder whether God has abandoned me.

1 - A great deal
2 - Quite a bit
3 - Somewhat
4 - Not at all

22. I try to make sense of the situation and decide what to do without relying on God.

1 - A great deal
2 - Quite a bit
3 - Somewhat
4 - Not at all

23. To what extent is your religion involved in understanding or dealing with stressful situations in any way?

1 - Very involved
2 - Somewhat involved
3 - Not very involved
4 - Not involved at all

Religious Support

These questions are designed to find out how much help the people in your congregation would provide if you need it in the future.

24. If you were ill, how much would the people in your congregation help you out?

1 - A great deal
2 - Some
3 - A little
4 – None

25. If you had a problem or were faced with a difficult situation, how much comfort would the people in your congregation be willing to give you?

1 - A great deal
2 - Some
3 - A little
4 – None

Sometimes the contact we have with others is not always pleasant.

26. How often do the people in your congregation make too many demands on you?

1 - Very often
2 - Fairly often
3 - Once in a while
4 – Never

27. How often are the people in your congregation critical of you and the things you do?

1 - Very often
2 - Fairly often
3 - Once in a while
4 – Never

Religious/Spiritual History

28. Did you ever have a religious or spiritual experience that changed your life?

1. No
2. Yes

IF YES: How old were you when this experience occurred?

29. Have you ever had a significant gain in your faith?

1. No
2. Yes

IF YES: How old were you when this occurred?

30. Have you ever had a significant loss in your faith?

1. No
2, Yes

IF YES: How old were you when this occurred?

Commitment

31. I try hard to carry my religious beliefs over into all my other dealings in life.

1 - Strongly agree
2 - Agree
3 - Disagree
4 - Strongly disagree

32. During the last year about how much was the average monthly contribution of your household to your congregation or to religious causes?

$_____ OR % income _____
Contribution per month Percent contribution per month

33. In an average week, how many hours do you spend in activities on behalf of your church or activities that you do for religious or spiritual reasons?
_____

Organizational Religiousness

34. How often do you go to religious services?

1 - More than once a week
2 - Every week or more often
3 - Once or twice a month
4 - Every month or so
5 - Once or twice a year
6 – Never

35. Besides religious services, how often do you take part in other activities at a place of worship?

1 - More than once a week
2 - Every week or more often
3 - Once or twice a month
4 - Every month or so
5 - Once or twice a year
6 – Never

Religious Preference

36. What is your current religious preference?

IF PROTESTANT Which specific denomination is that?

Overall Self-Ranking

37. To what extent do you consider yourself a religious person?

1 - Very religious
2 - Moderately religious
3 - Slightly religious
4 - Not religious at all

38. To what extent do you consider yourself a spiritual person?

1 - Very spiritual
2 - Moderately spiritual
3 - Slightly spiritual
4 - Not spiritual at all

Appendix G

FACIT-G (Version 4)

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

EMOTIONAL WELL-BEING

	Not At all	A little bit	Some-what	Quite a bit	Very much
I feel sad……	0	1	2	3	4
I am satisfied with how I am coping with my illness ……	0	1	2	3	4
I am losing hope in my fight against my illness ……	0	1	2	3	4
I feel nervous ……	0	1	2	3	4
I worry about dying ……..	0	1	2	3	4
I worry that my condition will get worse ……..……	0	1	2	3	4

FUNCTIONAL WELL-BEING

	Not At all	A little bit	Some-what	Quite a bit	Very much
I am able to work (include work at home)……	0	1	2	3	4
My work (include work at home) is fulfilling ……...	0	1	2	3	4
I am able to enjoy life ……	0	1	2	3	4
I have accepted my illness ……	0	1	2	3	4
I am sleeping well ……..	0	1	2	3	4
I am enjoying the things I usually do for fun ……..…	0	1	2	3	4
I am content with the quality of my life right now …….	0	1	2	3	4

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

PHYSICAL WELL-BEING

	Not At all	A little bit	Some-what	Quite a bit	Very much
I have a lack of energy …..……	0	1	2	3	4
I have nausea …… ……	0	1	2	3	4
Because of my physical condition, I have trouble ……..……0 meeting the needs of my family.		1	2	3	4
I have pain … ……..……0		1	2	3	4
I am bothered by side effects of treatment …….……..0		1	2	3	4
I feel ill ……0		1	2	3	4
I am forced to spend time in bed ……..0		1	2	3	4

SOCIAL/FAMILY WELL-BEING

	Not At all	A little bit	Some-what	Quite a bit	Very much
I fell close to my friends……	0	1	2	3	4
I get emotional support from my family …… ……...0		1	2	3	4
I get support from my friends.……0		1	2	3	4
My family has accepted my illness ……	0	1	2	3	4
I am satisfied with family communication about …….……..…. my illness	0	1	2	3	4
I feel close to my partner (or the person who is my ……..…0 main support)		1	2	3	4

Regardless of your current level of sexual activity, please Answer the following question. If you prefer not to answer It, please check this box □ and go to the next section.

I am satisfied with my sex life …… …….0		1	2	3	4

Appendix H

CES-D

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

During the Past Week

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	☐	☐	☐	☐
2. I did not feel like eating; my appetite was poor.	☐	☐	☐	☐
3. I felt that I could not shake off the blues even with help from my family or friends.	☐	☐	☐	☐
4. I felt I was just as good as other people.	☐	☐	☐	☐
5. I had trouble keeping my mind on what I was doing .	☐	☐	☐	☐
6. I felt depressed.	☐	☐	☐	☐
7. I felt that everything I did was an effort.	☐	☐	☐	☐
8. I felt hopeful about the future.	☐	☐	☐	☐
9. I thought my life had been a failure.	☐	☐	☐	☐
10. I felt fearful.	☐	☐	☐	☐
11. My sleep was restless.	☐	☐	☐	☐
12. I was happy.	☐	☐	☐	☐
13. I talked less than usual.	☐	☐	☐	☐
14. I felt lonely	☐	☐	☐	☐
15. People were unfriendly.	☐	☐	☐	☐
16. I enjoyed life.	☐	☐	☐	☐
7. I had crying spells.	☐	☐	☐	☐
18. I felt sad.	☐	☐	☐	☐

19. I felt that people dislike me.	☐	☐	☐	☐
20. I could not get “going.”	☐	☐	☐	☐

Appendix I

PANAS-X

This scale consists of a number of words and phrases that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few weeks. Use the following scale to record your answers:

1 2 3 4 5

very slightly a little moderately quite a bit extremely

or not at all

_____ cheerful _____ sad _____ active _____ angry at self

_____ disgusted _____ calm _____ guilty _____ enthusiastic

_____ attentive _____afraid _____ joyful _____ downhearted

_____ bashful _____ _ tired _ ____ nervous _____ sheepish

_____ sluggish _____amazed ___ lonely _____ distressed

_____ daring ____ __ shaky _____ sleepy _____ blameworthy

_____ surprised _____ happy _____ excited _____ determined

_____ strong _____ timid _____ hostile _____ frightened

_____ scornful _____ alone _____ proud _____ astonished

_____ relaxed _____ alert _____ jittery _____ interested

_____ irritable _____ upset _____ lively _____ loathing

_____ delighted _____ angry _____ ashamed _____ confident

_____ inspired _____ bold _____ at ease _____ energetic

_____ fearless _____ blue _____ scared _____ concentrating

_____ disgusted _____ shy _____ drowsy _____ dissatisfied with self with self

Appendix J

Religious Orientation Scale

Please indicate the extent to which you agree or disagree with each item below by using the following rating scale:

1	**2**	**3**	**4**	**5**
Strongly disagree	disagree	neutral	agree	strongly disagree

__1. Although I believe in my religion, I feel there are many more important things in my life.

__2. It doesn't matter so much what I believe so long as I lead a moral life.

__3. The primary purpose of prayer is to gain relief and protection.

__4. The church is most important as a place to formulate good social relationships.

__5. What religion offers me most is comfort when sorrows and misfortune strike.

__6. I pray chiefly because I have been taught to pray.

__7. Although I am a religious person I refuse to let religious considerations influence my everyday affairs.

__8. A primary reason for my interest in religion is that my church is a congenial social activity.

__9. Occasionally I find it necessary to compromise my religious beliefs in order to protect my social and economic well-being.

__10. One reason for my being a church member is that such membership helps to establish a person in the community.

__11. The purpose of prayer is to secure a happy and peaceful life.

__12. Religion helps to keep my life balanced and steady in exactly the same way as my citizenship, friendships, and other memberships do.

__13. It is important for me to spend periods of time in private religious thought and meditation.

__14. If not prevented by unavoidable circumstances, I attend church.

__15. I try hard to carry my religion over into all my dealings with life.

__16. The prayers I say when I am alone carry as much meaning and personal emotion as those said by me during services.

__17. Quite often I have been keenly aware of the presence of God or the Divine Being.

__18. I read literature about my faith (or church).

__19. If I were to join a church group I would prefer to join a Bible study group rather than a social fellowship.

__20. My religious beliefs are really what lie behind my whole approach to life.

__21. Religion is especially important because it answers many questions about the meaning of life.

Appendix K

Daily Spiritual Experiences Scale

	Many times a day	Every day	Most Days	Some Days	Once In a While	Never Or Almost never
I feel God's presence.						
I experience a connection to all of life.						
During worship, or at other times when connecting with God, I feel joy which lifts me out of my daily concerns.						
I find strength in my religion or spirituality.						
I find comfort in my religion or spirituality.						
I feel deep inner peach or harmony.						
I ask for God's help in the midst of daily activities.						
I feel guided by God in the midst of daily activities.						
I feel God's love for me, directly.						
I feel God's love for me, through others.						
I am spiritually touched by the beauty of creation.						
I feel thankful for my blessings.						
I feel a selfless caring for others.						
I accept others even when they do things I think are wrong.						
I desire to be closer to God or in union with the divine.						

	Not at all	Somewhat Close	Very Close	As close as possible
In general, how close do you feel to God?				

Appendix L

FACIT-Sp

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

	Not At all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
I feel peaceful……...…… 0		1	2	3	4
I have a reason for living …… ……0		1	2	3	4
My life has been productive …… ……..……0		1	2	3	4
I have trouble feeling peace of mind ……..0		1	2	3	4
I feel a sense of purpose in my life..……..……0		1	2	3	4
I am able to reach down deep into myself for comfort ……..0		1	2	3	4
I feel a sense of harmony within myself ……..…0		1	2	3	4
My life lacks meaning and purpose ……0		1	2	3	4
I find comfort in my faith or spiritual beliefs……..0		1	2	3	4
I find strength in my faith or spiritual beliefs……..0		1	2	3	4
My illness has strengthened my faith or spiritual beliefs……0		1	2	3	4
I know that whatever happens with my illness, things Will be okay……0		1	2	3	4

Appendix M

Spiritual Transformation Scale

For people who are spiritual or religious: This next set of questions asks about spiritual changes people sometimes have following a diagnosis of cancer. Spiritual changes might be negative or positive, small or large. These changes may or may not be true for you. Please think about any spiritual changes you may have experienced since your cancer diagnosis as you tell us how true each statement is for you.

For people who are <u>not</u> spiritual or religious: It is critically important that you complete this next set of questions so that your perspective is included in this study. Many statements may not apply to you. In this case, circling the number 1 will indicate that this has not been a part of your experience. Other statements may apply to you so please read carefully and tell us how true each of those statements is for you.

Whether you are or are not spiritual or religious, please indicate the extent to which these statements are true for you **since your diagnosis** of cancer. Think about how you were <u>before</u> you were diagnosed with cancer and how you are <u>now</u>. Circle the number that best describes any <u>changes</u> that have occurred using the following scale.

1	**2**	**3**	**4**	**5**	**6**	**7**
It is **not at all** true for you						It is true for you **a great deal**

Item
__1. Spirituality has become more important to me.
__2. My way of looking at life has changed to be more spiritual.
__3. Because of spiritual changes I've been through I've changed my priorities.
__4. I pay more attention to things that are spiritually important and forget about the little things that used to bother me.
__5. I pray or meditate more often.
__6. I spend more time taking care of my spiritual needs.
__7. I more often experience life around me as spiritual.
__8. I more often see my own life as sacred.
__9. I have a stronger spiritual connection to other people.
__10. I have a stronger spiritual connection to nature.
__11. Spiritually I am like a new person.
__12. Taking care of my body has taken on spiritual meaning.
__13. My relationships with other people have taken on more spiritual meaning.
__14. I have a stronger sense of the Sacred (God, Higher Power, Allah, Adonai, etc.) directing my life now.
__15. I act more compassionately towards other people since my diagnosis.
__16. I see people in a more positive light.
__17. I more often express my spirituality.
__18. I spend more time thinking about spiritual questions.
__19. I am more humble since my diagnosis.
__20. I more often think about how blessed I am.
__21. I have grown spiritually.
__22. I am more spiritually present in the moment.

__23. I take part in spiritual rituals more often.

__24. I more often have a sense of gratitude.

__25. I more often pray for other people.

__26. My spirituality is now more deeply imbedded in my whole being.

__27. I am more receptive to spiritual care from others (examples: prayer, healing practices, etc.).

__28. I more often look for a spiritual purpose for my life.

__29. I'm finding it more important to participate in a spiritual community.

__30. In some ways I am spiritually withdrawn from other people.

__31. My faith has been shaken and I am not sure what I believe.

__32. Spirituality seems less important to me now.

__33. In some ways I have shut down spiritually.

__34. In some ways I think I am spiritually lost.

__35. I feel I've lost some important spiritual meaning that I had before.

__36. My relationships with other people have lost spiritual meaning.

__37. I am more spiritually wounded.

__38. In some ways I am off my spiritual path.

__39. I more often think that I have failed in my faith.

__40. I am less interested in organized religion.

Appendix N

Completion of Study Questionnaire

Please answer the following questions. If the question has several possible answers circle the one that is most like the way you believe.

1. On your first visit to Northwest Alabama Cancer Center would you have preferred?

    1. Not to have religious/spiritual concerns addressed until you (the patient) brought them up.

    2. That you answer questions about religion/spirituality in your life by completing a paper-and-pencil survey rather than talking about it.

    3. That the physician asks about religion/spirituality just like he/she asks about past medical history, family history and social history.

    4. Not to discuss spiritual matters with your physician.

2. If you are asked to participate in another study involving religious/spiritual matters do you think you will be likely to participate?

    1. Yes

    2. No

3. If you had a religious/spiritual problem and told your physician about it, would you prefer that?

    1. the physician talks to you about your problem just like he/she would other medical and emotional problems you might ask about.

    2. the physician suggests you see your clergy.

3. that the physician refers you to someone else that might deal with the problem better that the physician (clergy, counselor, faith-based therapist).

4. that the physician refers you to a support group that addresses spiritual matters.

4. What is your opinion of physicians praying for patients?

1. Physicians should not pray for patients.

2. Physicians should pray for patients if the physician feels like he/she should.

3. Physicians should only pray for patients if patients ask them.

5. Is it ever ok for a physician to engage in religious/spiritual discussions with patients?

1. Yes

2. No

6. What best describes how you view the physician and patient interacting about spiritual matters?

1. The physician should always follow the lead of the patient

2. The physician may initiate on his/her own

7. Did you have religious/spiritual concerns or questions during the time you were treated for your cancer?

1. Yes

2. No

8. What was your single most important source of support for those spiritual concerns?

1. Family

2. Church/clergy

3. Physician

4. Self

5. Other

9. During the time of your diagnosis and initial treatment would you have welcomed?

1. Discussion by the doctor about religion/spirituality
2. Referral to a minister
3. Referral to a support group
4. Other

10. If you agreed to participate in a study aimed at improving your religion/spirituality would you prefer it to be?

1. at the time of your office visit
2. after work/ office hours
3. Doesn't matter

11. Do you think the 5 min video about the story of another cancer patient was helpful to you?

1. Yes
2. No

12. Was watching the 5min video about the story of another cancer patient in any way threatening to your current faith?

1. Yes
2. No

13. Do you think the video could be improved by providing a copy to take home?

1. Yes
2. No

14. Do you think the material presented in the video would be improved by providing Bible verses associated with the theme developed in the narrative?

1. Yes

2. No

15. Do you think the material presented in the video would be improved by providing associated music?

1. Yes

2. No

16. Should family members be involved in the viewing of the video with you?

1. Yes

2. No

18. Should your clergy be provided a copy of the video for them to review?

1. Yes

2. No

19. While watching the videos did you feel?

1. Comforted _____No _____Yes

2. Uplifted _____No _____Yes

3. Upset _____No _____Yes

4. Sad _____No _____Yes

5. Anxious _____No _____Yes

6. Anger _____No _____Yes

7. Peaceful _____No _____Yes

8. Loved by God _____No _____Yes

9. Loved by people _____No _____Yes

20. Do you believe it would have been helpful to you if Northwest Alabama Cancer Center provided a resource area aimed at meeting emotional and religious needs?

1. Yes

2. No

21. Would you make use of a quiet place set aside for prayer and meditation in the office?

1. Yes

2. No

22. Would you prefer to have a chaplain or pastoral care team available that is not affiliated with the office?

1. Yes

2. No

23. Have you at any time since your diagnosis of cancer felt that you needed to become more religious spiritual or spiritual?

1. Yes

2. No

Appendix O

Adverse Event Report

Adverse event description

_____

_____

_____

_____

Adverse event start date _____/_____/_____ (dd/mmm/yyyy)

Adverse event end date _____/_____/_____ (dd/mmm/yyyy)

Relation of adverse event to intervention

1 No relation

2 Doubtful

3 Possible

4 Probable

5 Likely

Changes made in response to adverse event

_____

_____

_____

_____

Specific treatment required for adverse event:

1 None

2 Office treatment _____

3 Hospitalizations

4 Other

Date of completion of study _____/_____/_____ (dd/mmm/yyyy)

Patient status at completion of study

Alive, treatment ended

Dead

Withdrew from study because _____

Loss to follow-up

Other

Appendix P

Case Report Forms

I. AT THE BEGINNING OF THE INTERVENTION STUDY

Subject ID number

Subject initials

Date of visit (dd/mmm/yyyy)

Date of informed consent

Date of enrollment

Gender and Ethnic group

Date of birth

Date cancer diagnosed and type of cancer

Initial examination (pertinent findings)

Vital signs

Performance status

Medications

II. DURING AND POST INTERVENTION

Week of study (intervention)

Date of study (intervention)

Type of intervention

Office location

Performance status

New medications

Scores on scales used

Appendix Q

Study Identification Log

Patients Name	**Study Identification Number***
1. _____	___-_____
2. _____	___-_____
3. _____	___-_____
4. _____	___-_____
5. _____	___-_____
6. _____	___-_____
7. _____	___-_____
8. _____	___-_____
9. _____	___-_____
10. _____	___-_____
11. _____	___-_____
12. _____	___-_____
13. _____	___-_____
14. _____	___-_____
15. _____	___-_____

***The first digit will be a letter representing the office location (F=Florence and M=Muscle Shoals) followed by the hyphen and then the patient number ranging consecutively form 01 to 20-.

Appendix R

IRB Approval Letter

Appendix J

Spiritually Oriented Narratives

Week One

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about her diagnosis and treatment and what she experienced and what she has told me helped her through that difficult time in her life.

When I first met this lady she was a 41 year old working mother of three beautiful children. She worked as homemaker, head start teacher and children's minister where she attended church. Prior to her diagnosis of cancer she described herself as the wife of a devoted husband and perfectly healthy—or so she thought. She had been experiencing increased tiredness and occasional migraine headaches. She scheduled an appointment with her family doctor and the examination revealed an enlarged lymph node below her jaw. After several founds of antibiotics the mass started growing. She underwent further testing and eventually a biopsy of the lump was done. After several days of anxiously waiting the diagnosis came back as metastatic squamous cell carcinoma, a cancer of the head and neck usually associated with tobacco and alcohol use. However, she did not smoke or drink alcohol. The cancer had originated from the base of the tongue on the right side.

She describes her initial reaction. "Cancer! What a terrifying word. There is an indescribable feeling that goes with that word. Since no one in my family had ever had

cancer, we really did not know what to expect. Fear of the unknown caused panic and numbness at the same time. I was shocked. How could this be happening to me?" She admitted to being angry at God.

There was one certainty in her life to which she held on. She said: "But I did know that I wanted to live. I wanted to see my children grow up and to grow old with my husband. So the greatest battle of my life began and I prayed constantly…"Lord, help me through this and please be with my family." And He did."

She was started on combined radiation therapy and chemotherapy in an attempt to shrink the tumor prior to attempts at surgery. She then underwent a radical neck dissection to remove the entire tumor and all lymph nodes. All together she received six months of intensive chemotherapy and 38 radiation treatments. During this time she found herself on an emotional roller coaster. She told me: "For six long months she and her family went through every emotion one could imagine. There was so much blind faith during the first few weeks. There were so many tests to be endured and there were visits to doctors that I did not know. But God led me to wonderful caring doctors who calmed my fears. He was with me though all the terrifying tests. There were "guardian angel" nurses who were with me through my darkest times."

The 91st Psalm became the source of strength for her though the treatment time. She told me that her husband or one of her children would read it to her on the days she was too sick to read it herself. She did question God during this time. She told me on one occasion: "On my weakest days the question was asked, "Why me Lord?" But the next day when I was stronger, I would say, "Why not me?" There were many valleys during those six months but my faith in God, my doctors and my family kept me going.

My husband became my caretaker, my nurse, “Mr. Mom”, and the housekeeper. I thank God for him everyday.”

Sometime during these difficult six months she experienced a moment when she realized worry was not accomplishing anything she really desired for her life. At this moment she decided to: “worry about nothing and pray about everything.” She admits it was hard to do. As soon as she found herself beginning to worry she would start praying. She found this became easier and easier and almost natural for her to do. “Worry about nothing and pray about everything” has become her motto.

When the chemotherapy and radiation therapy were completed she underwent an additional series of tests and x-rays. She heard another foreign term-- N.E.D. (no evidence of disease). She described these as “wonderful foreign words! God had healed me!”

When she told me her story she had been N.E.D. for two years. She continues to pray that she will stay that way. She has resolved that: “the fear of cancer coming back will not control my life. For now “I worry about nothing and pray about everything.” If the cancer does return, I will fight it again and my God will be with me.” These words were written over ten years ago and since that time she has experienced her children growing up and has grandchildren. Although she has suffered from some significant side effects of the radiation to her neck she continues to be without any evidence of the cancer returning. She remains active with her family and church.

One of the verses she continues to recall is: “Because he loves me, “Says the Lord, “I will rescue him.” I will protect him, for he acknowledges my name.” Psalms 91:14.

Week Two

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about his diagnosis and treatment and what he experienced and what he has told me helped him through this time.

The patient described his ordeal as turning tragedy into triumph. He was 22 years old when tragedy struck. It is a day that he said he would never forget. A routine doctor's visit literally changed and transformed his life. He remembers the exact minute he was diagnosed with cancer. His described his first thought: "I can't believe that this is happening to me!" and he stated: "I can still remember the way my heart raced and my knees shook."

In his words: "I thought my life was all over, but little did I know that my life had just begun. I had no idea how something as dreadful as cancer could turn out to be such a blessing in disguise. I was married and ready to graduate from college. Yet, I found myself empty and miserable. I would go to church and hear the preacher talk of a life of peace and joy, yet my life was so empty. I wanted peace and joy and I prayed 'Lord, whatever it takes to bring joy and peace to my life, I am willing to do.' When diagnosed with cancer I realized I could know God's character but not his plan. I can know His will but not always His Ways. I never dreamed that cancer would be the instrument He would use to bring joy and peace."

He went on to say: "One thing that has become very clear to me while battling cancer is that some things are so important to God that they are worth interrupting our health and happiness in order to accomplish them. I have learned to thank him for the valleys of life because that is where I have become more like him".

During his struggle with the diagnosis and subsequent treatment he found several things that helped in turning tragedy into triumph. In his own words: "(1) Reaffirm your position in Christ. (2) Ask God to remove the adversity from your life. This is where most of us begin and I am sure the Lord understands. Even Paul asked for his adversity to be removed. God did not chastise him. God will not be displeased because even a prayer of mercy is an expression of faith. (3) Reaffirm God's sustaining Grace. God may not choose to move quickly so we must rely on his Grace and not on our own strength. His grace will be sufficient moment by moment. (4) Thank and praise God for the opportunity to grow. We are not simply to endure suffering, but we are to grow and mature. The Christian life is a constant growing process. Adversity is God's most effective tool to make us more like Him. (5) Read and meditate on Scriptures. It sometimes helps to read of other people's struggles."

This young man went on to talk about suffering. He stated: "It is true that suffering is unavoidable. Suffering often takes us by surprise. It can shatter or strengthen us or it can be source of great bitterness or abounding joy. It can either destroy our faith or ground it even deeper. The outcome hinges on our responses. If you are a child of God whose heart's desire is to see God glorified through you, adversity will not put you down for the count. There will be an initial shock and confusion, but the person who has God's perceptive on this life and the life to come, will always emerge victorious."

"God healed me spiritually and also physically. When he told me his story he had been cancer free six years. That was eleven years ago. He said: "It is through cancer that God allowed me to preach his word. He provided me with an opportunity to earn a

seminary degree and the privilege to see hundreds of people come to know Him. I can now honestly say I am thankful for what cancer did and helped produce in my life."

He underwent treatment with chemotherapy that should have prevented him from fathering children. He and his wife have 3 boys. He has pastured churches in several states. When asked what he will do if the cancer comes back he replied "I can honestly say that is ok, because now I know Jesus is my life and He never fails. Galatians 2:20 says "I have been crucified with Christ and I no longer live, but Christ lives in me. The life I live in the body, I live by faith in the Son of God, who loved me and gave himself for me."

Week Three

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about her diagnosis and treatment and what she experienced and what she has told me helped her through this time.

The patient remembers clearly how she discovered what turned out to be cancer. She stated: "It was a beautiful day at the beach. The sun was shinning, the waves were crashing and life was good. We had just come in from swimming at the pool and were preparing to go out to dinner. It was time to shower, put on make-up, etc. During my shower, as I was washing, I felt a sore in my right breast. Not a big deal, I thought, women always have things going on like that, right? I just kind of shoved the thought to the back of my mind."

She went on to describe the events: “After returning home the month came in with a flurry of events. Several family members were very sick. I did notice, however, that the sore spot in my breast had turned into a lump. At this point, I began to really get worried.” The patient became afraid. She had had four aunts and a first cousin diagnosed with breast cancer and two of her aunts had died from the disease. She was seen by her gynecologist who sent her to a surgeon and she had a biopsy within a few days. She eventually had a radical mastectomy. She was 38 years old when she was diagnosed with breast cancer.

She describes how the next few weeks were filled with all kinds of emotions: “Was I going to die? What would my family do without me? I had a young husband, an eleven year old daughter and a sixteen year old son. I sank into a deep depression.” The patient believes that God, through her church family, helped her through these trying and difficult times. The entire church family prayed for her on a daily basis, sent her cards and special Bible verses, and books about how God can work in people’s lives during illnesses.

As soon as the mastectomy wound was healed she started on chemotherapy. Shortly after she started chemotherapy treatments her father-in-law died. In her words: “I was devastated. How could so many bad things happen to me? I think I gave a new meaning to the old saying ‘pity party’. What was going on? Where was my Lord and Savior? Why had He forsaken me? Does He not tell me in His word that He would no put on me more than I could bare? Not one time did I thank Him for not letting the cancer spread? I was only concerned with all the wrong things that were happening in my life. I had this fear inside of me telling me that I was going to die. Fear is not from

God, but only from the devil. My depression ended when my husband, who is a deacon in our church, came home from Sunday service and prayed the most beautiful prayer I have ever heard over me. It was like a great weight had been lifted off my shoulders. I was learning that His Grace is Sufficient."

She completed her chemotherapy treatments and started on radiation treatments. She had 26 treatments. She was very glad when they were over and soon realized that she was feeling pretty good. She described part of her experience: "Even though I was on one of the strongest kinds of chemo, the red devil, I never really experienced any sickness from it. I did lose all my hair but it came back prettier than it has ever been."

She considered reconstructive surgery at this time. She felt that it would help her personally, with what she had gone through. She was preparing for reconstructive surgery a few months later and had a pre-op chest x-ray. The x-ray showed a spot in her lungs. She stated: "Well, being a cancer patient and an ex smoker, you can imagine what was going through my mind. I was terrified to say the least. Here I go again for more tests. Will it ever end? The CAT scan was inconclusive and the PET scan came back negative. But, for me, this time was different. Even though it was a shock to hear the news, I still had a perfect peace about it." Eventually she underwent a thoracotomy (lung surgery to remove the lung mass) and the mass was benign. "Thank God!" she stated. She then proceeded with her reconstructive surgery.

When she told me her story she was preparing to leave for the beach again in a couple of weeks. She will celebrate three years of being cancer free in a few weeks. As she old me this story, she stated: "I have been looking back at my situation and thinking about how blessed I truly am. You see, God will use us in a lot of different ways if we

will let him. I am not saying that cancer or any disease is from God because I don't believe that. What I am saying is that sometimes He will allow us to go through trials to make us stronger. I have been able to witness to people that I would have never met otherwise. I know that there is hope and life for me in my Savior Jesus Christ. I also know that death has no victory over me. When my time comes I will finally meet my Lord. None of us are promised tomorrow."

She told me her story over a year ago. She remains free of any evidence of recurrence of cancer. She told me: "That is why I have learned to take one day at a time. I cherish every moment with my family and friends. I do not stress out over the small stuff. I know that God's grace and his mercy have healed me. My spiritual healing is far more important than my physical healing. I take the time to thank God for every moment that He has given me on this earth. I pray that He can use me daily for His Glory. I live life to its fullest. I don't worry about the past or the future. I live in the present because it is my gift from God."

Week Four

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about his diagnosis and treatment and what he experienced and what he has told me helped him through this time.

The patient was employed in the metal industry when I first met him. He was 53 years old. He saw his primary care physician for a routine examination. He was entirely asymptomatic. A screening flexible sigmoidscopy was recommended as routine screening and it revealed a mass in his colon. X-rays revealed a typical apple-core lesion

diagnostic of colon cancer. At the time of surgery he was found to have metastatic colon cancer. The colon cancer had spread to the liver. He underwent chemotherapy (almost four years) and was found to be in remission. That was in 1991. In 2002 he was found to have metastatic prostate cancer. The prostate cancer had moved to the bone. He continues on treatment today. He has had several treatments for the prostate cancer including hormonal therapy, radiation therapy and chemotherapy. He continues to be fully active.

When the patient was asked to describe his battle with cancer. He replied: "Blessing means to invoke divine favor. I don't know how else to explain what has happened to me over the last few years. I was inactive in church for a long time, but all during my absence from the church God was watching over me, keeping me pointed in the direction he had planned for me."

He describes the three times he has walked in the shadow of death and survived. In addition to the two cancers he had a large blood clot removed from this brain just two years before his diagnosis of colon cancer. During these times he knew many people prayed for him, helped him, and encouraged him. Each of these individuals is owed my eternal gratitude. Each, in his or her own way, helped keep me alive.

Apart from still being alive, I have been blessed many times over. I have seen my daughter graduate from college, and three weeks later escorted her down the aisle where I gave her in marriage and have been presented with two beautiful grandchildren. My son kept close watch on me through all my illnesses. The rest of my family is very supportive even though we lived hundreds of miles apart. The important things in my life changed from materialistic to inner human needs. I now know the peaceful serenity of

the countryside just before dawn, the beauty of a sunrise, the smell of rain, felt the softness of a rose petal and the soft warm breath of a baby on my cheek.

I have a friend at work who shared faith with me. She and I spent many lunch breaks reading our Bibles, talking about what we had read, and trying to get a better understanding. I will always believe God introduced me to her as part of his plan.

In June 1992, after I had been taking chemo for ten months and trying to lead as normal a life as possible, a baby was born to a friend. I became involved in the baby's life. I was there to see her learn to crawl, I was there to see her learn to walk, and I was there to see her learn to talk. I held her and rocked her when she was tired or not feeling well. I fed her, first from a bottle and then with a spoon. I bounced her on my knee and made her laugh. She was a joy to be around. I carried her when she was tired and couldn't walk anymore. There was no way I could have known that the last time I carried her would be as one of her pall bearers. She passed away suddenly at the age of eleven. As I stood at the grave site that November day, my heart heavy with grief and my eyes full of tears, I silently asked myself he questions that are as old as man. Why? What is happening there? This has to be a mistake! How can his be? But no answers came. In the last 14 months I have been to her grave site many times. Each time weeds are pulled, flowers rearranged or changed, but always no answer to why this happened. On my drive home after one of my visits I began thinking, not of her dying, but of the people she had touched in her short life. As I had suffered through the chemo treatments, always in my mind was the fact I had to feel good on Friday to go see her. I had to get better! It was then I realized that she kept me going, kept me alive! What a wonderful gift from God that he let me know this beautiful child for eleven years. I am truly blessed.

I have a renewed life with God. I feel myself grow as I regularly worship God and as I turn my cares over to God. Thanks, young child for helping me realize the important meaning of God's love and the plans he has for each of us.

The patient continues his treatment for metastatic prostate cancer. He is more active in his church. He has frequent opportunities to tell others of his blessings. It has been 15 years since his cancer was first diagnosed.

Week Five

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about her diagnosis and treatment and what she experienced and what she has told me helped her through this time.

The patient was a 53 year old housewife and mother of three children. She was busy with cooking and preparation for Thanksgiving celebration. She was glad she felt like being up and being active. She had a hysterectomy a few months earlier. However, she had an episode of passing blood in her bowel movements and underwent an evaluation with colonoscopy. She was found to have colon cancer and had removal of her tumor just before the holidays. The tumor extended through the wall of the colon. The cancer had already spread to lymph nodes. She told me: "No one wants to hear the words 'I'm sorry, but you have cancer.' I heard those words in 1996!" She had to start chemotherapy just before Christmas time. She had 36 chemotherapy treatments. She told me: "My strength came from my Lord and Savior Jesus Christ, from my family, my

friends, my church family and doctors and nurses that God placed in my life at that time. I thank Him every day for them still."

This housewife described what was important to her: "The most important thing to remember during this battle is your attitude. I did not give up hope and didn't consider cancer to be a death sentence. I turned it over to the Lord. It wasn't easy. I could not sit because of the weakness. I kept going. There were many nights I couldn't sleep. I was alone. My husband worked nights. My husband would call me whenever he had a chance at work. Sometimes we have to do things we really don't want to, as it was with my husband. We praise God for his job and this is what my husband had to do. My Lord was always there. Some nights I was so weak I would actually reach my hand up to Him and ask Him to take hold of it to give me strength. What a sweet and peaceful time that was. Just me and Him. I realized that I am His child and I should be thankful in every situation or circumstance. He taught me that through this battle."

She had this to say about her diagnosis and treatment for colon cancer. "I prayed a lot for strength and courage to go on. My God is sufficient in all things. We go through, I believe, trials and hardships for a reason. In time God will let us see that reason."

She had told me that she actually thanks God for the experience of having cancer. She told me of four reasons. "First, it taught me to trust Him completely, because this wasn't anything I could do to help myself. My family and friends supported me, but only God could give me the strength and courage to face this trial. Oh, I had wonderful Christian doctors who encouraged me and yes, also cared for me. But no one loves me like Jesus. You see, doctors have to pray too for guidance and wisdom. It's all in His

hands. I was going to be healed. If not on this earth, I would go home to be with my Lord. There I would be made whole and my body would no more have any disease or pain. There would be no more tears or sorrows. So I was already a winner! I was a victor in Him! Praise the Lord! Second, it taught me to love others as Christ loves us. Unconditionally. We are to accept people for who they are faults and all. This is a tremendous lesson to learn. Third, it taught me compassion. This is a reason that has really touched my life and made it better. I see people differently than I used to. It has allowed me to really see those who are hurting and in need of encouragement. We are going to help others along the way. Isn't that great?! God is in control. During the last 8 1/2 years, God has placed many people in my path. Through the love and compassion that He has taught me, I was able to encourage and help those who were and are going through this trial. Cancer is a trial and a battle. You see, I know their fears, I know how they feel, and most of all I know what God can and will do if you place yourself in his care. He will bring you through. That's the most important reason for going through this battle, its being sure you know Him personally. We are His and He is ours. What a comforting experience to know Him. There's hope and healing in Him. My fourth and finally reason for going through this trial, I believe, is prayer. I did a lot of talking to my Father. My prayer life is so much stronger. So I'm thankful for all the things I was taught during this battle. But most of all I got to know my Savior and learn to trust and depend on Him daily, not just on Sunday."

In summary she had this to say: "I'm a better person today for going through this trial in my life. So look up, take hold of His mighty hand. He won't let go! He's the great physician and your best friend in time of trouble."

She is now almost 64 years old. It has been ten years since her cancer was diagnosed. She continues without any evidence of recurrence and lives her life daily to its fullest.

Week Six

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about his diagnosis and treatment and what he experienced and what he has told me helped him through this time.

The patient was first diagnosed with cancer in 1999. He was 65 years old. In the fall of 1999 he experienced some chest pain and saw his family doctor who referred him to a heart specialist. The patient underwent a heart catherization to determine if he had any blockage of his heart vessels. After the procedure the cardiologist told the patient and wife that he had good news and bad news. The good news was that the heart vessels showed no blockage. He was not having any heart pain. The bad news was that the he found a spot on his lungs that needed further investigation.

The cardiologist recommended a thoracic surgeon review the records. The patient told me that: “The fact that the cardiologist noticed the spot on my lung had to be God’s intervention. God has a way of showing Himself as our all seeing, all knowing one in the negative areas of our lives.”

The surgeon eventually decided the mass could be removed and the patient underwent surgery. The middle lobe of his right lung was removed. He did have an emergency situation arise during surgery but that was soon resolved. He later told me his

thoughts after the surgery when he learned of how close he came to dying: “Through all this…when you wonder what will be next…God says ‘Trust Me’.” That’s exactly what I did. The patient’s favorite verse was Proverbs 3:5-6: “Trust in the Lord with all your heart and lean not into thine own understanding. In all thou ways acknowledge him, and He will direct thy paths.”

When he had surgery all the lung cancer was removed. At that time chemotherapy was not recommended. However, since that time new findings indicate he should have received at least 4 months of chemotherapy to reduce his chance of the cancer coming back. However, that was not known in 1999.

In early 2004 the patient was found to have a mass in the left lower lung area and a needle biopsy revealed it to be squamous cell carcinoma. The patient was now 70 years old and was not medically able to undergo surgery because of his previous smoking having damaged his lungs.

The patient old me when this tumor was found he remembered his previous thoughts about God saying “Trust Me.” The verse that was important to the patient during this time was 1 Peter 5:7: “Casting all your care upon him; for he careth for you.” The decision was made to treat the patient with chemotherapy and radiation therapy. At this time the patient was still working and very active. He recalled another verse that helped him during this time--Hebrews 11:1: Now faith is the substance of things hoped for, the evidence of things not seen.

During this time he had some difficulty swallowing and low blood counts but completed his treatment in late spring. He was very weak. He was hospitalized for pneumonia. The decision was made to stop any further chemotherapy for the time being.

About nine months later he developed shingles with severe pain. In early 2005 there was evidence the lung cancer was active again. He had regained his strength and wished to proceed with treatment.

With the latest chemotherapy came lung infections, low blood counts, physical weakness, and the possible need for oxygen. He told me during this time: "I know having faith is not ignoring the problem; it's knowing that we have a God who is with us to see us through. He is our peace and our hope. The Lord calms our fears. We know in whom we have believed and He is able to keep us!"

After three months of chemotherapy the patient was experiencing side effects from his chemotherapy and his cancer was not growing and the decision was made to allow his to gain some of his strength back. Since that time he has taken treatments for a few months and then rested a few months. He recalled the verse in Isaiah 26:3-4: Thou wilt keep him in perfect peace, whose mind is stayed on thee, because he trusteth in thee. Trust ye in the Lord forever; for in the Lord Jehovah is everlasting strength." He also reads Jeremiah 33:3 quite a lot: "Call unto me, and I will answer thee, and show thee great and might things which thou knowest not."

The patient is receiving chemotherapy again. He remains very active even with his lung damage from cigarette smoking and the effects of chemotherapy. He has a positive outlook on life. He remains active in church. Recently he was able to tell me: "As we face each new phase of our lives, we trust God to give us faith, peace and the hope that can only come from knowing that we move and have our being by God's grace and mercy."

It has now been seven years from his initial diagnosis. He has undergone surgery, radiation therapy and several chemotherapies. He continues to be active.

Appendix T

Factually Oriented Narratives

Week One

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about her diagnosis and treatment and what she experienced and what she has told me helped her through that difficult time in her life.

When I first met this lady she was a 41 year old working mother of three beautiful children. She worked as homemaker, head start teacher. Prior to her diagnosis of cancer she described herself as the wife of a devoted husband and perfectly healthy—or so she thought. She had been experiencing increased tiredness and occasional migraine headaches. She scheduled an appointment with her family doctor and the examination revealed an enlarged lymph node below her jaw. After several founds of antibiotics the mass started growing. She underwent further testing and eventually a biopsy of the lump was done. After several days of anxiously waiting the diagnosis came back as metastatic squamous cell carcinoma, a cancer of the head and neck usually associated with tobacco and alcohol use. However, she did not smoke or drink alcohol. The cancer had originated from the base of the tongue on the right side.

She describes her initial reaction. "Cancer! What a terrifying word. There is an indescribable feeling that goes with that word. Since no one in my family had ever had

cancer, we really did not know what to expect. Fear of the unknown caused panic and numbness at the same time. I was shocked. How could this be happening to me?"

There was one certainty in her life to which she held on. She said: "But I did know that I wanted to live. I wanted to see my children grow up and to grow old with my husband. So the greatest battle of my life began.

She was started on combined radiation therapy and chemotherapy in an attempt to shrink the tumor prior to attempts at surgery. She then underwent a radical neck dissection to remove the entire tumor and all lymph nodes. All together she received six months of intensive chemotherapy and 38 radiation treatments. During this time she found herself on an emotional roller coaster. She told me: "For six long months she and her family went through every emotion one could imagine. There were so many tests to be endured and there were visits to doctors that I did not know.

My husband became my caretaker, my nurse, "Mr. Mom", and the housekeeper"

Sometime during these difficult six months she experienced a moment when she realized worry was not accomplishing anything she really desired for her life. At this moment she decided to: "worry about nothing." She admits it was hard to do.

When the chemotherapy and radiation therapy were completed she underwent an additional series of tests and x-rays. She heard another foreign term-- N.E.D. (no evidence of disease). She described these as "wonderful foreign words!

When she told me her story she had been N.E.D. for two years. She has resolved that: "the fear of cancer coming back will not control my life. For now "I worry about nothing." If the cancer does return, I will fight it again." These words were written over ten years ago and since that time she has experienced her children growing up and has

grandchildren. Although she has suffered from some significant side effects of the radiation to her neck she continues to be without any evidence of the cancer returning. She remains active with her family.

Week Two

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about his diagnosis and treatment and what he experienced and what he has told me helped him through this time.

The patient described his ordeal as turning tragedy into triumph. He was 22 years old when tragedy struck. It is a day that he said he would never forget. A routine doctor's visit literally changed and transformed his life. He remembers the exact minute he was diagnosed with cancer. His described his first thought: "I can't believe that this is happening to me!" and he stated: "I can still remember the way my heart raced and my knees shook."

In his words: "I thought my life was all over, but little did I know that my life had just begun. I had no idea how something as dreadful as cancer could turn out to be such a blessing in disguise. I was married and ready to graduate from college."

He went on to say: "One thing that has become very clear to me while battling cancer is that some things are so important that they are worth interrupting our health and happiness in order to accomplish them."

This young man went on to talk about suffering. He stated: "It is true that suffering is unavoidable. Suffering often takes us by surprise. It can shatter or

strengthen us or it can be source of great bitterness or abounding joy. The outcome hinges on our responses.

When he told me his story he had been cancer free six years. That was eleven years ago. He said: “It is through cancer that I was provided an opportunity to earn a college degree and the privilege of seeing the benefits of my work. I can now honestly say I am thankful for what cancer did and helped produce in my life.”

He underwent treatment with chemotherapy that should have prevented him from fathering children. He and his wife have 3 boys. When asked what he will do if the cancer comes back he replied “I can honestly say that is ok.

Week Three

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about her diagnosis and treatment and what she experienced and what she has told me helped her through this time.

The patient remembers clearly how she discovered what turned out to be cancer. She stated: “It was a beautiful day at the beach. The sun was shinning, the waves were crashing and life was good. We had just come in from swimming at the pool and were preparing to go out to dinner. It was time to shower, put on make-up, etc. During my shower, as I was washing, I felt a sore in my right breast. Not a big deal, I thought, women always have things going on like that, right? I just kind of shoved the thought to the back of my mind.”

She went on to describe the events: “After returning home the month came in with a flurry of events. Several family members were very sick. I did notice, however, that

the sore spot in my breast had turned into a lump. At this point, I began to really get worried." The patient became afraid. She had had four aunts and a first cousin diagnosed with breast cancer and two of her aunts had died from the disease. She was seen by her gynecologist who sent her to a surgeon and she had a biopsy within a few days. She eventually had a radical mastectomy. She was 38 years old when she was diagnosed with breast cancer.

She describes how the next few weeks were filled with all kinds of emotions: "Was I going to die? What would my family do without me? I had a young husband, an eleven year old daughter and a sixteen year old son. I sank into a deep depression." As soon as the mastectomy wound was healed she started on chemotherapy. Shortly after started chemotherapy treatments her father-in-law died. In her words: "I was devastated. How could so many bad things happen to me? I think I gave a new meaning to the old saying 'pity party'. What was going on?

I was only concerned with all the wrong things that were happening in my life. I had this fear inside of me telling me that I was going to die…" She related to me that her depression ended one day after being comforted by her husband. She stated: "It was like a great weight had been lifted off my shoulders."

She completed her chemotherapy treatments and started on radiation treatments. She had 26 treatments. She was very glad when they were over and soon realized that she was feeling pretty good. She described part of her experience: "Even though I was on one of the strongest kinds of chemo, the red devil, I never really experienced any sickness from it. I did lose all my hair but it came back prettier than it has ever been."

She considered reconstructive surgery at this time. She believed that it would help her personally, with what she had gone through. She was preparing for reconstructive surgery a few months later and had a pre-op chest x-ray. The x-ray showed a spot in her lungs. She stated: "Well, being a cancer patient and an ex smoker, you can imagine what was going through my mind. I was terrified to say the least. Here I go again for more tests. Will it ever end? The CAT scan was inconclusive and the PET scan came back negative. But, for me, this time was different. Even though it was a shock to hear the news, I still had a perfect peace about it." Eventually she underwent a thoracotomy (lung surgery to remove the lung mass) and the mass was benign. She then proceeded with her reconstructive surgery.

When she told me her story she was preparing to leave for the beach again in a couple of weeks. She will celebrate three years of being cancer free in a few weeks. As she old me this story, she stated: "I have been looking back at my situation and thinking about how blessed I truly am.

She told me her story over a year ago. She remains free of any evidence of recurrence of cancer. She told me: "That is why I have learned to take one day at a time. I cherish every moment with my family and friends. I do not stress out over the small stuff. I live life to its fullest. I don't worry about the past or the future. I live in the present…"

Week Four

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about his diagnosis and treatment and what he experienced and what he has told me helped him through this time.

The patient was employed the metal industry when I first met him. He was 53 years old. He saw his primary care physician for a routine examination. He was entirely asymptomatic. A screening flexible sigmoidscopy was recommended as routine screening and it revealed a mass in his colon. X-rays revealed a typical apple-core lesion diagnostic of colon cancer. At the time of surgery he was found to have metastatic colon cancer. The colon cancer had spread to the liver. He underwent chemotherapy (almost four years) and was eventually found to be in remission. That was in 1991. In 2002 he was found to have metastatic prostate cancer. The prostate cancer had moved to the bone. He continues on treatment today. He has had several treatments for the prostate cancer including hormonal therapy, radiation therapy and chemotherapy. He continues to be fully active.

When the patient was asked to describe his battle with cancer.
He talked about the three times he has walked in the shadow of death and survived. In addition to the two cancers he also had a large blood clot removed from this brain just two years before his diagnosis of colon cancer. During these times he knew many people helped him and encouraged him. Each of these individuals is owed my eternal gratitude. Each, in his or her own way, helped keep me alive.

I have seen my daughter graduate from college, and three weeks later escorted her down the aisle where I gave her in marriage and have been presented with two beautiful

grandchildren. My son kept close watch on me through all my illnesses. The rest of my family was very supportive even though we live hundreds of miles apart. The important things in my life changed from materialistic to inner human needs. I now know the peaceful serenity of the countryside just before dawn, the beauty of a sunrise, the smell of rain, felt the softness of a rose petal and the soft warm breath of a baby on my cheek.

In June 1992, after I had been taking chemo for ten months and trying to lead as normal a life as possible, a baby was born to a friend. I became involved in the baby's life. I was there to see her learn to crawl, I was there to see her learn to walk, and I was there to see her learn to talk. I held her and rocked her when she was tired or not feeling well. I fed her, first from a bottle and then with a spoon. I bounced her on my knee and made her laugh. She was a joy to be around. I carried her when she was tired and couldn't walk anymore. There was no way I could have known that the last time I carried her would be as one of her pall bearers. She passed away suddenly at the age of eleven. As I stood at the grave site that November day, my heart heavy with grief and my eyes full of tears, I silently asked myself he questions that are as old as man. Why? What is happening there? This has to be a mistake! How can his be? But no answers came. In the last 14 months I have been to her grave site many times. Each time weeds are pulled, flowers rearranged or changed, but always no answer to why this happened. On my drive home after one of my visits I began thinking, not of her dying, but of the people she had touched in her short life. As I had suffered through the chemo treatments, always in my mind was the fact I had to feel good on Friday to go see her. I had to get better! It was then I realized that she kept me going, kept me alive

The patient continues his treatment for metastatic prostate cancer. He is more active. He has frequent opportunities to tell others of his blessings. It has been 15 years since his cancer was first diagnosed.

Week Five

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about her diagnosis and treatment and what she experienced and what she has told me helped her through this time.

The patient was a 53 year old housewife and mother of three children. She was busy with cooking and preparation for Thanksgiving celebration. She was glad she felt like being up and being active. She had a hysterectomy a few months earlier. However, she had an episode of passing blood in her bowel movements and underwent an evaluation with colonoscopy. She was found to have colon cancer and had removal of her tumor just before the holidays. The tumor extended through the wall of the colon. The cancer had already spread to lymph nodes. She told me: "No one wants to hear the words 'I'm sorry, but you have cancer.' I heard those words in 1996!" She had to start chemotherapy just before Christmas time. She had 36 chemotherapy treatments. She told me: "My strength came from my family, my friends, family and doctors and nurses."

This housewife described what was important to her: "The most important thing to remember during this battle is your attitude. I did not give up hope and didn't consider cancer to be a death sentence. It wasn't easy. I could not sit because of the weakness. I kept going. There were many nights I couldn't sleep. I was alone. My husband worked nights. My husband would call me whenever he had a chance at work. Sometimes we

have to do things we really don't want to, as it was with my husband. Some nights I was so weak.

"My family and friends supported me. I had wonderful doctors who encouraged me and yes, also cared for me. . Having cancer "taught me to love others unconditionally." We are to accept people for who they are faults and all. This is a tremendous lesson to learn. I learned compassion. This is a reason that has really touched my life and made it better. I see people differently than I used to. It has allowed me to really see those who are hurting and in need of encouragement. We are going to help others along the way. Isn't that great?! I am able to encourage and help those who were and are going through this trial. Cancer is a trial and a battle. You see, I know their fears, I know how they feel.

In summary she had this to say: "I'm a better person today for going through this trial in my life.

She is now almost 64 years old. It has been ten years since her cancer was diagnosed. She continues without any evidence of recurrence and lives her life daily to its fullest.

Week Six

I would like to tell you a story about someone diagnosed with cancer and treated in this office a few years ago. Please listen as I tell you about his diagnosis and treatment and what he experienced and what he has told me helped him through this time.

The patient was first diagnosed with cancer in 1999. He was 65 years old. In the fall of 1999 he experienced some chest pain and saw his family doctor who referred him

to a heart specialist. The patient underwent a heart catherization to determine if he had any blockage of his heart vessels. After the procedure the cardiologist told the patient and wife that he had good news and bad news. The good news was that the heart vessels showed no blockage. He was not having any heart pain. The bad news was that the he found a spot on his lungs that needed further investigation.

The cardiologist recommended a thoracic surgeon review the records. The surgeon eventually decided the mass could be removed and the patient underwent surgery. The middle lobe of his right lung was removed. He did have an emergency situation arise during surgery but that was soon resolved.

When he had surgery all the lung cancer was removed. At that time chemotherapy was not recommended. However, since that time new findings indicate he should have received at least 4 months of chemotherapy to reduce his chance of the cancer coming back. However, that was not known in 1999.

In early 2004 the patient was found to have a mass in the left lower lung area and a needle biopsy revealed it to be squamous cell carcinoma. The patient was now 70 years old and was not medically able to undergo surgery because of his previous smoking having damaged his lungs.

The decision was made to treat the patient with chemotherapy and radiation therapy. At this time the patient was still working and very active.

During this time he had some difficulty swallowing and low blood counts but completed his treatment in late spring. He was very weak. He was hospitalized for pneumonia. The decision was made to stop any further chemotherapy for the time being. About nine months later he developed shingles with severe pain. In early 2005 there was

evidence the lung cancer was active again. He had regained his strength and wished to proceed with treatment.

With the latest chemotherapy came lung infections, low blood counts, physical weakness, and the possible need for oxygen.

After three months of chemotherapy the patient was experiencing side effects from his chemotherapy and his cancer was not growing and the decision was made to allow him to gain some of his strength back. Since that time he has taken treatments for a few months and then rested a few months.

The patient is receiving chemotherapy again. He remains very active even with his lung damage from cigarette smoking and the effects of chemotherapy. He has a positive outlook on life.

It has now been seven years from his initial diagnosis. He has undergone surgery, radiation therapy and several chemotherapies. He continues to be active.

Appendix U

Spiritually Oriented Videos

Appendix V

Factually Oriented Videos

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